Experiences of adult patients living with home parenteral nutrition: a grounded theory study.

A qualitative research into the experiences of home parenteral nutrition: discovery of patients' perspectives.

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Abstract

Introduction

Patients with intestinal failure (IF) develop problems of malabsorption and malnutrition associated with short bowel syndrome (SBS). Home parenteral nutrition (HPN) became available to treat these patients since the 1970s. There is a paucity of qualitative research on patients' experiences in the UK. The study aim was to generate theory that explains the experiences of adults living with HPN and complex medication regimens.

Method

The grounded theory methodology was used to explore the experiences and to generate theory about this health intervention. Twelve participants were interviewed. The interviews were recorded and transcribed verbatim. The joint process of data collection and analysis followed the principles of constant comparative approach.

Results

The core categories of stoma care and HPN treatment were supported by the subcategories of maintaining stoma output, access to toilets, maintaining HPN infusion routine, access to technical help to set up HPN infusion, and general health changes. Strategy used to manage living with loss was demonstrated by the subcategory of maintaining daily activities and social interactions.

Discussion

The theory of living with loss suggests that patients with a stoma receiving HPN experience the sense of loss at home and in social situations. Opportunities for professional practice development are detailed along with implications for future research.

Conclusions

The findings resonate with the Kubler-Ross Model of the five stages of grief (Kubler-Ross, 1970). The theory of living with loss was generated by the use of the grounded theory methodology. This study identified opportunities for changes and improvement in clinical practice.

Acknowledgement

'Not everyone can be equally skilled at discovering theory, but neither do they need to be a genius to generate useful theory' (Glaser and Strauss, 1967 p.viii)

My sincere thanks to the patients who agreed to be interviewed for this study. Their willingness and openness to share their stories and experiences have been admirable. They have provided the healthcare professionals with an insight into their lives with home parenteral nutrition. Their experiences have contributed to the findings of this exploratory research study.

I would like to thank my supervisors, Dr Beverley Lucas and Dr Diana Wood (University of Bradford) for their expert guidance, support and encouragement during all the stages of the research process.

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Publication

Some of the materials from the literature review of this thesis have been accepted for publication (Wong et al., 2015). A copy of this publication which was released online in 2014 is included in Appendix 1.

List of abbreviations

ASPEN	American Society of Parenteral and Enteral Nutrition
BANS	British Artificial Nutrition Survey
CCGs	Clinical Commissioning Groups
CINAHL	Cumulative Index to Nursing and Allied Health Literature
HPN	Home Parenteral Nutrition
HPN-QoL	Home Parenteral Nutrition Quality of Life
HRQOL	Health Related Quality Of Life
HTAs	Health Technology Assessments
IBDQ	Inflammatory Bowel Disease Questionnaire
IF	Intestinal Failure
IRAS	Integrated Research Application System
LCT	Long Chain Triglycerides
MeSH	Medical Subject Headings
NICE	National Institute for Health and Care Excellence
NGH	Northern General Hospital
NMP	Non Medical Prescriber
NPSA	National Patient Safety Agency

NRES	National Research Ethics Services
NST	Nutrition Support Team
QoL	Quality of Life
PIN	Parenteral Nutrition
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
PINNT	Patients on Intravenous and Naso-Gastric Nutrition Therapy
PN	Parenteral Nutrition
RHH	Royal Hallamshire Hospital
RFIPC	Rating Form of Inflammatory Bowel Disease Patient Concerns
SBS	Short Bowel Syndrome
SF 36	Short Form 36
SIP	Sickness Impact Profile
WHO	World Health Organisation

Referencing

This thesis follows the Harvard (Brad) style.

Chapter 1 INTRODUCTION

This chapter describes the history of parenteral nutrition, the development and the formulation of the admixture, which contains amino acids, glucose, long chain and medium chain triglycerides, electrolytes, trace elements and vitamins (water- and fat-soluble). This informs readers of the scientific context of parenteral nutrition, and its use in disease management and treatment. This is followed by the economic consideration of impact of home parenteral nutrition (HPN) and the provision of home parenteral nutrition services by nutrition support teams in the UK.

1.1 History of parenteral nutrition

Parenteral nutrition (PN) is one of many well established technology-assisted treatments available to patients worldwide. It is defined as the administration of nutrition intravenously to patients with non-functioning and / or non-accessible gut as the result of underlying disease or complication from surgical procedures (Scribner, 1970). The development of parenteral nutrition was not an overnight process. It took surgeons and scientists in basic and biomedical sciences over 400 years of investigations and experiments to make this treatment modality safe and effective in management of a range of diseases (Vinnars and Wilmore, 2003). In order to appreciate the clinical importance of parenteral nutrition, I have included an overview of the developments and achievements made by researchers from different scientific disciplines. The development of central venous access and catheter materials will not be discussed here.

The discovery of blood circulation by William Harvey in 1628 was important in understanding human anatomy and the early concept of intravenous infusions (Wretlind, 1992, Dudrick, 2009). In 1656 Sir Christopher Wren, a physiologist and physician, used a quill and a pig's bladder to inject a mixture

of wine, ale and opium into a dog's vein. He found the dog became drunk as if it had taken the alcohol orally (Barsoum and Kleeman, 2002). This became Wren's historical experiment which paved the way for subsequent research and development of intravenous injections.

1.2 Studies with glucose and protein hydrolysate solutions

In 1856 Claude Bernard discovered the role of glucose metabolism in cells (Vinnars and Wilmore, 2003). A 10% glucose solution was injected into humans for the first time by Arthur Beidl and Rudely Krauts in 1896 (Dudrick and Rhoads, 1971). Later scientists learnt that dietary proteins were broken down in the intestines before absorption. In 1913, two Danish researchers infused a beef hydrolysate with glucose and electrolytes intravenously into goats and they found a positive nitrogen balance in all the animals (Henriques and Anderson, 1913). Nitrogen balance describes the relationship between the amount of nitrogen taken into the body and that excreted from the body in urine and faeces. A positive nitrogen balance was observed by Henriques and Anderson (1913) and this demonstrated that the intake of nitrogen in the form of a beef hydrolysate by the goats was greater than its excretion. Dudrick et al. (1968) infused this beef hydrolysate into dogs and they reported their findings on amino acid metabolism. By the 1930s William Rose identified the essential amino acids in humans, and this work signalled the beginning of a new research focus on the use of this amino acid mixture for protein synthesis in humans (Vinnars and Wilmore, 2003).

1.2.1 Experiments in animals

In 1937 Robert Elman, an American surgeon, injected a mixture of glucose and protein hydrolysate made from casein, into dogs. He found positive nitrogen balance in these animals (Elman, 1937). From these findings other scientists became interested in the use of intravenous protein hydrolysates

as a source of dietary protein in humans. 1n 1939 Elman and Weiner successfully infused a solution of fibrinogen hydrolysate into post-operative patients and patients with inoperable cancer. They found positive nitrogen balance in both groups (Vinnars and Wilmore, 2003). These results led to the emergence of a new focus on the concept of intravenous nutrition (Cuthbertson and Stewart, 1945).

1.2.2 Experiments in humans

By the early 1940s scientists had developed the first artificial amino acid mixture and this was used intravenously in humans (Macht, 1980). These early studies generated results which encouraged further research into the body's metabolic responses to injury and starvation, and the possibility of feeding humans intravenously with protein and carbohydrate. This marked the beginning of parenteral nutrition.

1.3 Development of parenteral nutrition

During the 1940s and 1950s hospital patients who were too ill to eat were kept alive on intravenous glucose infusion alone. Clinicians believed that *'feeding entirely by vein is impossible; even if it were practical, it would be unaffordable'* (Dudrick, 2009 p 246). Patients were starved for days until they could eat and drink again. There was a lack of understanding and awareness of the negative impact of malnutrition on morbidity, mortality and wound healing.

A paper published by Studley in 1936 raised awareness of poor survival post-surgery and poor nutritional status in adult patients (Studley, 2001). Some clinicians infused high concentrations of glucose solution (10 to 20%) in order to provide more calories. These solutions caused phlebitis. Surgical patients often experienced malnutrition because the operation itself could cause or

worsen catabolism. In general, abdominal surgery affects normal gut function by reducing gut motility or causing malabsorption of nutrients during the post-operative period (Dudrick, 2003).

1.3.1 Experiments in animals and humans

Groups of surgeons became interested in developing methods to provide nutritional support to malnourished patients. Early meticulous experiments in dogs provided data on nitrogen metabolism (Rhode et al., 1949). In 1968 a group of American surgeons used an intravenous infusion of protein hydrolysates and concentrated glucose to feed six Beagle puppies. All of them survived on this admixture (Dudrick et al., 1968). These same researchers repeated the experiment using this puppy formula in new-born infants and adults with severe gastrointestinal diseases. They reported weight gain, positive nitrogen balance, growth and development in all of them (Dudrick et al., 1969). This admixture of protein and glucose became the basis of parenteral nutrition (PN).

1.3.2 Formulation of parenteral nutrition admixtures

During the 1950s and 1960s patients in the United States were fed parenteral nutrition based on amino acids and hypertonic glucose. Many of them developed clinical signs of essential fatty acid deficiencies: dermatitis increased capillary permeability, hair loss, liver and kidney damage and reduced platelet production. This led to the infusion of a fat emulsion separately in order to provide essential fatty acids. In 1963 a lipid emulsion made from soya bean oil emulsified with egg yolk phospholipids was found to be safe for human use (Schuberth and Wretlind, 1963). This long chain triglyceride (LCT) infusion, Intralipid^{TM}, became the first commercially available product for use in human nutritional support.

Between 1960 and 1970 individual nutrient infusions were formulated in glass bottles (protein in the form of amino acid solution, carbohydrate in the form of glucose solution, and fat in the form of long chain triglyceride emulsion). Nurses added electrolytes, vitamins and trace elements to the glucose solutions before they were infused over 24 hours. Patients were kept in hospital for the entire treatment duration.

By the mid-1970s significant pharmaceutical development in emulsion stability and innovation in material science had made it possible to have all three nutrients (amino acids, glucose and lipid), vitamins plus electrolytes, available in one collapsible infusion container (Vinnars and Wilmore, 2003). Nowadays PN admixtures consist of sterile and nutritionally balanced macronutrients and micronutrients for intravenous administration.

1.4 Parenteral nutrition: clinical need in disease management

In a study of six adult surgical patients, they were given an intravenous infusion of the basic nutrient solution developed by Dudrick (Dudrick et al., 1969). This one litre solution contained six grams of nitrogen and 1000 calories (1 kcal/ml) (Serlick et al., 1969). Serlick et al. found positive nitrogen balance, weight gain, normal wound healing, and these patients reported increased strength, activity and sense of wellbeing in a variety of catabolic clinical situations. This experiment marked the beginning of the use of parenteral nutrition as a treatment modality to overcome the catabolic effects of trauma and stress.

1.4.1 Intestinal failure

Since the 1960s surgeons have become more aware of the complications of delayed wound healing and increased infection from protein-calorie malnutrition in post-operative patients. Patients who have undergone complex abdominal operations, or have developed surgical complications

which cause dysfunction of the gut, may require parenteral nutrition support for many weeks and months.

Parenteral nutrition can save lives in patients who have intestinal failure (IF) (Scribner et al., 1970). IF is a condition associated with extensive loss of absorptive function and capacity of the small intestines (Johansson et al., 1976). There are many different causes for IF ranging from obstruction (Faulk et al., 1978), abnormal motility, major surgical resection, congenital defects and severe inflammatory bowel disease (Carlson, 2003). The main problem in IF is the failure of the small bowel to absorb nutrients (fat, protein and carbohydrate), water, minerals and vitamins from the diet to maintain health or sustain life (Harrison and Booth, 1960).

1.4.2 Short bowel syndrome

Patients with IF may develop a range of health problems and the term 'short bowel syndrome' (SBS) is used to describe the clinical consequences caused by IF (Scolapio, 2002). –Wanten et al. defined short bowel syndrome as a subgroup of IF when less than 200 cm of small intestines remain (or 75% is lost) as the result of surgery, bowel disease, or a congenital defect (Wanten et al., 2011 p696). These patients with SBS are unable to maintain protein-energy balance, fluid balance, electrolyte balance, and micronutrient balance when eating a normal diet.

1.4.3 Malabsorption and malnutrition

Before the discovery of PN in the 1960s patients with SBS would die from chronic malabsorption and malnutrition (Harrison and Booth, 1960). These patients become reliant on PN in order to meet nutritional and fluid requirements (Richards and Irving, 1996). They are at risk from malnutrition and dehydration if the treatment is stopped on discharge from hospital. Many

of them need to continue PN at home, and without this treatment their health will suffer and they will die from dehydration and kidney failure.

1.5 Home parenteral nutrition

During the 1970s and 1980s clinicians in the USA started to provide PN at home to adults who suffered chronic IF due to non-malignant diseases (Dudrick et al., 1984). Home parenteral nutrition (HPN) involves the delivery and administration of a sterile admixture containing optimally balanced macronutrients, micronutrients and electrolytes in a single infusion bag at the patient's home. The patient has a long-term indwelling central venous catheter for administration of the PN admixture. Patients or their main carers have to learn the skills and aseptic techniques needed to set up the infusion, and to connect to the catheter at home overnight. In some cases patients receive help from the specialist nurses, who look after the central venous catheter and carry out the connection and disconnection of the HPN feed. Once the patients are clinically and metabolically stable with the infusion during hospital stay, they continue with HPN following discharge. Patients with chronic IF from SBS receiving HPN can continue with oral diet and fluids, but they need to follow a low residue diet advised by dietitians. Some of these patients also take oral medications to reduce losses from ileostomies or chronic severe diarrhoea (Nightingale, 2001). Patients with severe, chronic malabsorption become dependent on lifelong treatment with HPN. They live with this healthcare intervention in the same way as do those with chronic health conditions.

In relation to patient experiences, the administration of PN at home imposes additional demands on the individuals' daily lives. HPN treatment requires individuals to learn and follow strict aseptic techniques in order to prevent the development of infection of the central venous catheter used for infusion (Dudrick et al., 1984). Dudrick et al. (1984) provided a detailed description of the practical aspects of HPN from more than 100 patients-years' experience.

The HPN infusion took between twelve to fourteen hours at a frequency which varied from daily to three or five times a week. The long infusion time placed restrictions on the range and choice of social and domestic activities for the individuals. Other equipment had to be kept at home, for example a refrigerator for HPN infusion bags, infusion pump, drip stand, dressing trolley, sterile dressing packs and other sterile disposable items (Dudrick et al., 1984).

1.6 Economic impact of home parenteral nutrition

During the early 1970s a total of fourteen adult patients were trained to continue the administration of parenteral nutrition at home (Scribner et al., 1970). This pioneering practice of home parenteral nutrition (HPN) spread rapidly across the rest of the United States, to Canada and to some European countries (Mughal and Irving, 1986). During this time the main focus was on the clinical outcome of HPN patients with little or no references being made to costs of this therapeutic intervention to the overall health expenditure (Puntis, 1998).

In 1980 Wateska et al. examined the total costs to a hospital which provided HPN to eight patients over a two year period (Wateska et al., 1980). They identified many cost components including patient training, infusion equipment, sterile consumables and disposable equipment, out-patient follow-up clinics, administrative costs such as ordering, invoicing and transportation. They estimated that the average annual cost per patient receiving HPN was US $19,700, compared with the estimated cost of US $73,720 for 1 year of PN as an in-hospital patient (Wateska et al., 1980). The authors concluded that HPN was considerably more cost-effective than in-patient hospital care.

Between 1989 to 1992, approximately 120 patients per 1 million US residents were HPN recipients (Winkler, 2005 p162), with an estimated cost of US

$150,000 to US $200,000 per patient year based on figures from the late 1980s (Howard et al., 1991). This could be a reflection of the advance in both surgery and the availability of parenteral nutrition in the community. A review published by Winkler et al stated that 7,000 people in the US received long term or life-long parenteral nutrition (Winkler, 2005). This makes HPN an expensive therapy.

By 1994 the HPN cost in the UK was estimated to be around £55,000 per patient year in the community (Elia, 1995). The Kings Fund Report (Lennard-Jones, 1992 p.24) summarised the different components for HPN: rental payments for electrical infusion pumps, infusion stand, and refrigerator used to store feed solutions, payment for preparation of feed solution and associated supplies such as sterile dressing packs, swabs, infusion administration sets, and light protective covers for feeds. HPN treatment involves a range of non-drug related expenditures, making the total cost of HPN much higher than those for other chronic health conditions such as hypertension or diabetes. The small number of patients living with HPN in the UK meant that this health technology remains poorly researched. There is little published information on the economic impact of providing HPN.

1.7 Demand for HPN

Many patients with SBS were offered this ambulatory treatment with HPN in many Western countries (Howard et al., 1995, Elia, 1995). In 1977 St Mark's Hospital, London discharged the first patient on HPN (Jones, 2003). The North American HPN Patient Registry reported a prevalence of 120 per million population for HPN between 1989 and 1992 (Howard et al., 1995). In 1993 a European retrospective survey from 13 countries and 75 centres, involving adult patients with non-malignant primary disease receiving HPN, reported an incidence of 0.2-4.6 and a prevalence of 0.3-12.2 patients per million population per year (Van Gossum et al., 1996).

In the UK and the Republic of Ireland, 200 patients were registered as receiving HPN between January 1977 and March 1986. They were managed by 28 centres with seven centres being responsible for 75% of these patients (Mughal and Irving, 1986). The hospitals were spread across different parts of England (Salford Royal Hospital, 58 patients; St Mark's Hospital, London 30 patients; King's Cross Hospital, Dundee 16 patients; Newcastle-upon-Tyne 15 patients; St Mary's Hospital, Portsmouth 14 patients; Northern General Hospital, Sheffield 12 patients; Leeds General Infirmary 12 patients). In 1997 a UK health technology assessment identified differences between countries on the underlying diseases for which HPN is indicated (Richards et al., 1997). It reported that HPN was offered to more patients with an underlying malignancy in Italy and the USA than in the UK (40-70% versus 8%) (Richards et al.,1997).

In 2008 the UK National Commissioning Group published a report on the 'Strategic framework for intestinal and home parenteral nutrition services for adults in England' (2008). It reported that 18 adult patients per million population require prolonged management of IF in hospitals, and 14.6 adult patients per million population need HPN on discharge from hospital (NHS National Commissioning Group for Highly Specialised Services, 2008).

In 2011 the British Artificial Nutrition Survey (BANS) published data collected from 2000 to 2010 (Smith, 2011). The reported UK HPN point prevalence was 8.40 per million population during 2010. This survey also found that SBS was the most common reason for HPN (54.4% new cases; 58.9% established cases). Crohn's disease, small bowel ischaemia and pseudo-obstruction were the major indications for new HPN cases (18.4%, 9.7% and 11% respectively) and established cases (29.3%, 15.3% and 15.1%).

In 2010 there were 228 new adult patients registered for HPN, compared with 148 in 2009 and 157 in 2008, representing a rise in clinical demand in the UK (Smith, 2011). In contrast 3,430 adults were newly registered for home enteral tube feeding in 2010 (Smith, 2011). The number of newly registered adult patients receiving HPN was low in comparison with other common chronic health conditions such as hypertension and diabetes. Therefore, only a very small number of GPs are likely to come across an HPN patient in their practices.

1.8 Sheffield home parenteral nutrition support team

The Sheffield HPN team at Royal Hallamshire Hospital (RHH) has been looking after patients receiving HPN since the early 1990s. Over the years patients with severe intestinal failure from nearby cities in South Yorkshire (Barnsley, Rotherham, Doncaster and Bassetlaw) and as far afield as Boston and Mansfield, have been referred to them for HPN.

By April 2012, the Sheffield HPN team had between 23 and 25 adult patients on their register. In 2011 to 2012, the estimated annual cost for 23 HPN patients living in five South Yorkshire Primary Care Trusts (PCTs) was over £653,000. After the PCTs were changed to Clinical Commissioning Groups (CCGs), the Sheffield HPN team continued to negotiate with the commercial homecare companies directly for the cost and delivery of HPN feeds, and all the ancillary items for each patient receiving HPN. In April 2013 the funding arrangement for HPN was changed from CCGs to NHS England as one of the specialised services.

The Sheffield HPN team is a multi-disciplinary team which consists of a consultant gastroenterologist, an associate chemical pathologist, a clinical nurse specialist, a dietitian and a pharmacist. At HPN out-patient clinics, patients are reviewed and assessed in terms of general health, body weight,

feeding problems and care of the Hickman line used for feed administration. Blood samples are taken for routine serum biochemistry measurements, and these are used to check for kidney and liver functions. The team uses these objective measurements to assess the patient's clinical response to HPN. During the consultation, the clinician writes in the medical notes other issues raised by patients about their HPN treatment. However, there is a lack of research or evaluation of this information from the patient's perspective.

The prescriptions for the HPN feeds are written by the medical prescribers of the HPN team. These prescriptions are dispensed by approved, licensed homecare companies. GPs are not involved in the regular review and clinical monitoring of patients receiving HPN, or the organisational aspects of the HPN feed deliveries. As non-medical prescriber (NMP) for in-patients who require parenteral nutrition, my clinical practice is based at the Northern General Hospital (NGH). I do not have prescribing input to HPN patients under the care of the Sheffield HPN team.

1.8.1 Training for new patients receiving HPN

Patients who need to continue PN at home receive training provided by the clinical nurse specialist of the HPN team during their hospital stay. This training consists of the aseptic technique which is needed to make connections and disconnections between the central venous catheter, or Hickman line, and the HPN feed infusion administration set. These patients also learn to change the sterile dressing which is used to protect the skin exit site of the Hickman line.

The duration of HPN training in hospital varies from three to five weeks, depending on the patients' ability to learn the aseptic technique needed to look after the Hickman line, and to connect the administration set to the feed safely. For patients who are unable to carry out the aseptic procedure safely, these patients receive twice a day home nursing visits provided by the

homecare company. The nurse visits the patient in the evening to set up the HPN feed, and then in the following morning to disconnect the infusion. In order to reduce the length of hospital stay for some patients who have been in hospital for over three months, they have chosen to receive HPN training provided by the homecare company nursing team at home instead.

1.8.2 Follow ups for new patients receiving HPN

The nursing team from the homecare company maintains contact with each new patient receiving HPN by regular telephone calls and home visits. The nursing team provides technical support to the patient in the operation of the infusion pump, as this equipment is different from the one used on the ward at the local hospital. These nursing visits usually discontinue after two weeks, and these nurses provide verbal feedback on the patient's progress to the clinical nurse specialist of the HPN team.

All patients receiving HPN have telephone access to the clinical nurse specialist of the HPN team during normal office hours from Mondays to Fridays. Patients are encouraged to contact the clinical nurse specialist and ask for advice on care of the Hickman line or any aspects of the HPN treatment. The clinical nurse specialist will advise if the patient needs to contact the GP for non-HPN related issues, or if the individual needs to attend the accident and emergency department in the case of a suspected catheter-related infection. The patient's GP receives a discharge summary letter from the HPN team. The GP is not involved in the review of a patient receiving HPN in the community as this is done by the Sheffield HPN team.

1.8.3 HPN outpatient clinics

All HPN patients are reviewed by the HPN team at out-patient clinics, which are held every six to eight weeks following hospital discharge. During the fifteen minutes consultation the patient's body weight is measured, the

Hickman line skin site is swabbed for routine microbiological screening, and a blood sample is taken to check renal function and serum electrolyte levels (sodium, potassium, urea, creatinine, albumin, calcium, phosphate and magnesium). The Sheffield HPN team has not had the opportunity to carry out an evaluation of patients' experiences with HPN.

1.8.4 Patients living with HPN

The latest BANS report explored the HPN patients' *'ability to manage'* and their *'activity level'* (Smith, 2011 p.35). It found that 60.1% and 71% of newly registered adult patients were described as independent and fully independent respectively for ability to manage following discharge from hospitals. For activity level it found that only 68% of patients were described as fully active, whilst nearly 40% required some help or total help at home. From this latter group, limited activity was reported by 28.5%, with 3.5% and 2.5% remaining house-bound or bed-bound respectively. The report did not give details on what help was needed by these patients, or who provided the help. All data were submitted by healthcare professionals of the nutrition support teams from 21 HPN centres. They assessed the patients and then directly submitted the data onto the collection forms. The data represented limited insight into the patients' experiences with HPN.

1.8.5 Patients' experiences with the National Health Service

In 2008 Lord Darzi's report 'High quality care for all' (Department of Health, 2008) highlighted the importance of the entire patient experience with the NHS. In 2012 the NICE clinical guidance number 138 provided the NHS with clear guidance on the components of a good patient experience (NICE, 2012). It emphasized the need for service providers to ensure services are designed in a way that respond to the needs, preferences and values of the patient. It also recommended that service providers should encourage the

patients to give feedback about their care, and the providers should respond to any feedback given (NICE, 2012).

Patient representation on the committee for 'Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England' (NHS National Commissioning Group for Highly Specialised Services, 2008) provides a valuable contribution to the design and commissioning of HPN services across the UK. The availability of published qualitative data on patients' experiences living with HPN could support the National Clinical Commissioning Group when making decisions on the provision and improvement of intestinal failure and home parenteral nutrition services for adults in England.

1.9 Reflexivity

As consultant pharmacist of the nutrition support team, I receive referrals from surgical and medical teams to provide nutritional support to patients with acute intestinal failure. In a few cases patients with an ileostomy from complex surgical procedure or extensive bowel resection developed chronic intestinal failure when they failed to maintain nutrition and hydration with oral diet and fluids. I also work closely with the stoma care nurse specialists, who provide me with regular feedback on these patients' progress with stoma care and their responses to medications intended to reduce stoma losses.

In a few cases patients with persistently high stoma losses remain dependent on supplementary PN, despite full compliance with dietary restrictions and medications. I have been involved in the referral of patients with chronic intestinal failure to the Sheffield HPN team for long term nutritional support in the community. Once these patients have been transferred to the care of the HPN team, I do not have any clinical or prescribing input to them. I have

often wondered how these patients manage stoma care and HPN treatment at home.

I have previous experience in designing and conducting service audits in clinical settings. I have no previous practice or experience with qualitative research. The current study has provided me with the opportunities to put into action the knowledge gained from the module on qualitative research methodologies at stage 1 of the DPharm programme, and to develop confidence and insight into all the processes involved in designing, planning, conducting, analysing and managing a small scale research study.

1.10 Rationale for research area

Following a conversation with the consultant gastroenterologist and other members of the Sheffield HPN team, they revealed that there is no mechanism in place locally to assess these patients' experiences with HPN. The HPN team relies on patients' feedback on their wellbeing at regular outpatient clinics, in addition to the various objective measurements being made at each visit.

During a recent visit by our clinical nurse specialists to the two national intestinal failure centres, they commented on the variations in the range of services provided by Sheffield and the national centres. The main difference is that at St Marks Hospital, London and at Royal Salford Hospital, they have a psychologist who provides clinical support to HPN patients. We do not know if our HPN patients experience the same or different psychological and psychosocial issues as those reported by researchers in the US and other European countries.

This confirms some of the findings reported in the NHS Research & Development Health Technology Assessments (HTAs) carried out by Richard et al. (1997) which criticised the poorly conducted assessment on quality of life (QoL) of patients receiving HPN in UK, and a lack of comparative data in the organisation and provision of HPN service by NST from different hospitals (Berry et al., 2011). This HTA recommends measurement and comparison of patient experience with HPN as well as comparison of episodes of catheter sepsis, occlusion, central vein thrombosis and metabolic imbalance from different UK HPN centres. There is a gap in the knowledge and understanding of the impact of HPN on these patients' lives at home and in local communities.

The patients' experiences living with HPN in the UK remain unknown. This question provides the context for this small scale research study. This gave me the impetus to conduct a research study which explores the experiences of patients receiving HPN, and to find out if their experiences are similar or different from those in the published literature. The findings from this study may be used to highlight opportunities for professional practice development and for future national research.

1.11 Chapter summary

The advancement in scientific and pharmaceutical development has led to the availability of sterile parenteral nutrition admixtures to treat patients with chronic intestinal failure. The introduction of HPN teams has been instrumental in providing training, support and monitoring of patients who are dependent on parenteral nutrition to maintain health. Patients receiving HPN have improved physical health (Wanten et al., 2011), but they have to integrate this health intervention into their daily lives.

Chapter 2 LITERATURE REVIEW

2.1 Introduction to chapter

A literature review is described as an objective critical analysis of the relevant available research and non-research literature on the topic being studied (Cronin et al., 2008). A literature review has an important role in identifying the findings from published research studies, and using these to decide what is worth investigating, and how this may be done (Denscombe, 2003 p.115). In the case of qualitative research studies, the literature review is valuable in locating the current knowledge and theory, and identifying the gap which justifies the research question on a particular topic (Holloway and Walker, 1999).

This chapter provides a review of existing literature demonstrating the current understanding on the lived experiences of patients receiving HPN. The gap in knowledge revealed by these published studies supports how this current study could generate new discoveries on the qualitative impact of this health intervention in the patients' everyday lives.

2.2 Literature review and the grounded theory methodology

The grounded theory approach has gained popularity in its use as a methodology for qualitative studies of human interactions (Denscombe, 2003 p.109). The role of the literature review in a qualitative research study using the grounded theory methodology has been debated by researchers since Glaser and Strauss first presented their new approach to the generation of theory from data using the method of constant comparative analysis (Glaser and Strauss, 1967 p.1-2).

Glaser and Strauss advised researchers using the grounded theory methodology to *'ignore the literature of theory and fact on the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas'* (Glaser and Strauss, 1967 p.37). This means researchers who follow Glaser and Strauss's approach avoid the temptations of *'forcing round data into square categories when justifying explanation for the relationship between the two'* (Glaser and Strauss, 1967 p.37).

Glaser and Strauss (1967) advocated that the researchers' lack of awareness of established theories about a topic is crucial in supporting the generation of new categories, discouraging the researchers' preferences in data selection. In practice this 'open-mind' approach is both unique and central to the classic grounded theory methodology. Glaser and Strauss's original publication (1967) did not intend for the researcher to start a research study with *'a focus, a general question, or a problem in mind. But he can (and we believe should) also study an area without any preconceived theory that dictates, prior to the research, 'relevances' in concepts and hypothesis'* (Glaser and Strauss, 1967 p.33). In practice this principle of the grounded theory encourages the researcher to develop a sense of discovery during the research process (Denscombe, 2003 p.111).

Grounded theorists such as Charmaz (2006) and Corbin and Strauss (2008) have provided additional insights on the role of a literature review in a grounded theory study. Charmaz (2006) advises that the literature review helps the researchers to: clarify the idea of the topic being researched; make comparison with what has been published on the topic being considered; and support how the findings from the proposed study may fit the gap in current knowledge (Charmaz, 2006 p.165-168). Corbin and Strauss (2008) stated

that the literature can be *'a stimulus to research',* (Corbin and Strauss, 2008 p.22) pointing to a topic which has not been studied.

The researcher's awareness of published literature on a topic may highlight the need to use a different approach to address the uncertainties. In the case of healthcare settings, professionals may come across a problem in a clinical setting for which there is no known answer. Narrative research focuses on individual stories provided by participants, whilst phenomenological study analyses common experiences from a group of participants (Creswell, 2013). When studying social interactions or experiences with the aim to explain a process, not to test or verify an existing theory, the use of grounded theory approach is appropriate (Creswell, 2013). This is because a grounded theory study goes beyond description provided by participants; the researcher develops higher level understanding of a process or an action that is grounded in, or derived from, data analysed (Glaser and Strauss, 1967). This current small scale research study follows the grounded theory approach in order to support the generation or discovery of theory explaining the experiences of adult patients living with home parenteral nutrition. In a situation like this the researcher's experience with the provision of parenteral nutrition support service to patients with intestinal failure may become the touchstone of an exploratory study, and the development of theory may help to explain practice or to provide a framework for further research. The published literature could be used to safeguard the appropriateness of the proposed study. A more detailed discussion on the ground theory approach is set out in chapter 3, section 3.5.

In order to support the application of this research study to the local research ethics committee and to the National Research and Ethics Committee (NREC), healthcare research requires a detailed proposal as part of the ethics applications. I have to include references to published literature which

support the research study proposal. The use of literature search is in conflict with grounded theorists but this is unavoidable.

2.3 Strategy for literature search

I have followed the processes of a narrative review of the literature using a defined approach when searching and discussing the literature in the topic area of home parenteral nutrition. The readers can assess the reliability and validity of the published literature used by me in support of the research question. This ensures that I have demonstrated a balanced approach when identifying gaps or inconsistencies in existing knowledge, and when defining the research question (Cronin et al., 2008).

This review encompasses a broad range of published international research studies, as well as official publications from the Department of Health, National Institute for Health and Care Excellence (NICE), registered patient charitable organisations and publications prepared by specialist interest groups. The electronic databases used, the keywords used as search terms and the criteria for inclusion and exclusion used to select and identify the relevant published studies will be discussed in the following sections.

2.3.1 Search databases, search focus and terms used

The following databases were used to include both the scientific and the healthcare disciplines, reflecting the multidisciplinary nature of providing HPN treatment to patients with chronic intestinal failure. Each database was searched using the keywords for relevant articles published from January 1970 to December 2013.

- Medline

- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- Web of Science (formerly Web of Knowledge)

Medline provides a broad range of the majority of the medical and pharmaceutical publications. CINAHL was searched as this was the bibliographic database for nursing and allied health professions covering both nursing and biomedical journals. Web of Science (formerly Web of Knowledge) was accessed through the citation manager EndNote Web for the social science citation index.

The search focus included the following areas of interest:

- Experiences of adult patients with intestinal failure;
- Experiences of adult patients with intestinal failure and parenteral nutrition at home;
- Quality of life in patients with intestinal failure and parenteral nutrition long term;
- Problems experienced by patients with parenteral nutrition long term.

The search terms used varied depending on the database used. For example the Medline database uses different Medical Subject Headings (MeSH) to those used by CIHAHL and Web of Knowledge. The terms used for each database were minor variations on the following keywords:

- Home parenteral nutrition
- Intestinal failure
- Patient experiences
- Quality of life

Only studies which had been published in the English language were included in the search. Additional studies were included from reference lists of eligible papers, including Department of Health publications, National Institute for Health and Care Excellence (NICE) clinical guidance, UK charities, and patient support / self-help groups with interests in HPN or IF, and NHS England publications.

2.3.2 Inclusion criteria

Qualitative studies that assessed or evaluated home parenteral nutrition and patients' experiences with parenteral nutrition at home respectively were included. Eligible patients were those who could eat and drink but were also partially or fully dependent on HPN (with or without additional intravenous fluids, with or without antimotility drugs for chronic malabsorption and malnutrition problems associated with intestinal failure, and lived in the community (privately or in residential / nursing homes). All causes of intestinal failure in patients with non-malignancy were included. Patients who are medically too ill to or who have learning disabilities will be excluded from the study. It is felt that they would be unable to express their views and experiences independently without the help of carers or family members. These were included in the application form submitted to the NHS research ethics service (NRES).

2.3.3 Exclusion criteria

Studies which examined the clinical outcome of HPN, involved children as participants, and those published in a language other than English were excluded.

2.3.4 Review process

A detailed description of the processes followed in order to identify the published literature and studies available from the above electronic databases is available in Appendix 2 Literature review search strategies. The abstracts identified from each database were checked for relevance, and those which did not have a connection to the research topic were rejected at this stage. Abstracts which met the inclusion criteria were downloaded as full text or pdf documents. Published guidance (Spencer et al., 2003) for the critiquing of qualitative research studies was used to appraise these studies. The reference list from each key review article was used to identify additional publications relevant to the research topic. The research study focus was on patients' experiences with HPN, therefore, it was necessary to include publications prepared by government organisations, specialist interest groups, and registered patient charitable organisations.

2.4 Findings of the literature review

The results of the literature review are now presented as thematic areas identified within the literature.

2.4.1 Staying alive with HPN

During the 1970s and 1980s the clinical outcomes of HPN were studied by many researchers in the UK, the USA and European countries. They reported on the prevention of certain death of twelve patients who received home parenteral nutrition through a silicone rubber catheter introduced into the superior vena cava from 4 months to 5 years (Jeejeebhoy et al., 1976), reduction in hospital stay (Greig et al., 1981), remission of bowel obstruction due to Crohn's disease (Rault and Scribner, 1977), weight gain in all nineteen patients who had received HPN for an average of 25.5 months (range 3–90 months) (Fleming et al., 1980), and improved biochemical

profiles in 48 out of 106 patients who remained on the home parenteral nutrition programme (Byrne et al., 1979). Researchers in the USA published their results on more than 100 patient-years' experience of treating 133 patients with HPN using a range of central venous catheters made with different materials between 1974 and 1983 (Dudrick et al., 1984). These researchers' focus was on keeping these patients alive and monitoring for side effects of treatment such as catheter-related infection episodes (Dudrick et al., 1984). There was a case report of a patient, who had been on HPN for approximately 24 months, and developed an alcoholic hepatitis-like reaction. She needed HPN following a massive intestinal resection caused by a mesenteric occlusion. This patient developed progressive hepatic disease despite attention to caloric, amino acid, lipid, trace metal and vitamin supplementation (Craig et al., 1978).

2.4.2 Living a life with HPN

One American study used a qualitative methodology to observe 19 patients treated with HPN at home. The researchers found that these patients experienced psychological problems of anger, anxiety, depression, loss of ability to eat, negative body image and relationship problems (Price and Levine, 1979). Another study was conducted by an American homecare company, which used semi-structured interviews first and then the researchers (a psychiatrist and a psychiatric nurse) observed 10 patients receiving HPN over two years. They reported similar findings of depression, fear, anxiety, body image distortion, marital stress and sexual difficulties (Perl et al., 1981). This study concluded that there was a need for further research into the cause of depression associated with HPN, the biological / cognitive effects of the treatment modality, and the role of psychotropic agents in treating HPN patients who developed these symptoms (Perl et al., 1981). These discoveries led to changes in the research paradigm with subsequent investigations focusing on the impact of HPN on patients' quality of life.

2.4.3 Quality of life indicators

The World Health Organisation (WHO) defines Quality of Life as:

> *'An individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal benefits and their relationship to salient features of their environment'* (WHO, 1997).

Away from the healthcare setting, Calman (1984) suggests that *'the quality of life can only be described and measured in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions'*. He advocates that *'quality of life must include all areas of life and experience and take into account the impact of illness and treatment'* (Calman, 1984 p.124).

In 1989 a written questionnaire survey on home parenteral nutrition was carried out by a major USA home care company. Of the 1140 HPN patients who were sent written questionnaires, it was reported that half of the 347 patients who had completed the survey were less satisfied with life as a whole in comparison to the overall United States population and to those with end stage renal disease (Herfindal et al., 1989). The mean length of time respondents had been receiving home parenteral nutrition was 35 months. The quantitative study supported the need for further research into the QoL of HPN patients.

Carlsson et al. (2003) studied 28 patients with intestinal failure due to short bowel syndrome (19 female, 9 male; mean age 54 years) who were in need

of nutritional therapy, (oral, enteral and/or intravenous), in order to maintain a stable body weight). This quantitative study recorded the QoL using a visual analogue scale in both study patients and matched controls. The researchers assessed the Health-related quality of life (HRQOL) using Short Form 36 (SF-36), and they found that patients who were dependent on HPN rated a lower QoL than those without HPN (Carlsson et al., 2003). The researchers provided a breakdown on the HPN and non-HPN patient characteristics: 8 of the 28 study patients were dependent on HPN, 18 of the 28 had a stoma. Six of the 18 patients with stoma were dependent on HPN, and amongst these 6 patients 3 of them had a jejunostomy. Despite the small number of HPN patients in this study, the patient characteristics and the presence of a jejunostomy had provided relevance to the Sheffield HPN patients who were recruited into this current small scale research study. Carlsson et al., (2003) echoed Calman's statement in their discussion and concluded that, when asking a subject to rate personal QoL we must appreciate what this concept means to him / her.

Most studies on patients receiving HPN used generic quantitative assessment tools to evaluate QoL. Ladefoged used a simple ordinal scale of poor, fair or good to measure QoL in a psychosocial survey of patients dependent on HPN (7 female, 6 male; age range 24-62 years, median 53 years, mean HPN duration range 2-43 months) (Ladefoged, 1981). These patients were also interviewed, as well as partners of 11 patients who were married or cohabiting. They were asked specific questions about physical symptoms, social and leisure activities, interpersonal relationships, sexuality, psychological problems, and feelings about HPN. All the HPN patients were unemployed but only 6 (46%) were able to take part in housekeeping tasks. Psychological symptoms were recorded in 6 HPN patients (46%), 7 partners considered HPN to be a moderate or severe burden, and it was mainly psychological changes in the HPN patient that caused marital tension in 3 cases. The researcher described the criteria for QoL: 1) no major physical

distress, 2) no major psychological symptoms, 3) no substantial restriction of social and leisure activities, 4) ability to accept HPN, 5) overall satisfaction with conditions of life. The researcher repeated the interviews at intervals of 6-10 months in 9 patients, and did not find systematic improvement or deterioration of QoL during HPN. This study used mixed methods and the findings highlighted the multi-factorial and complex association between HPN as a treatment modality and its effect on both the patients and their partners.

Detsky et al. (1986) measured the QoL in terms of quality-adjusted survival in 73 HPN patients (53% female / 47% male, age range 19 – 75, mean age 41.7 years) who had been on HPN from 6 months to 12 years. This quantitative study used three utility assessment techniques: category scaling, time-trade off, and direct questioning of objectives. These researchers reported that the estimated quality-adjusted survival was four times greater with HPN than with alternative therapeutic strategies ($p<0.001$) (Detsky et al., 1986). The findings from this study (Detsky et al., 1986) could not be used to compare with publications by other researchers as it used different QoL assessment techniques. Others published studies used existing generic or non-disease specific sickness impact profile (SIP), which was developed to measure perceived health status (Bergner et al.,1981). Non-disease specific SIP was sensitive enough to detect changes or differences in health status occurring over time or between groups. The non-disease specific SIP was used in quantitative studies to assess QoL in different types and severities of illness, and across demographic and cultural subgroups (Jeppesen et al., 1999).

Jeppesen et al. (1999) used both the non-disease specific SIP questionnaire and the inflammatory bowel disease questionnaire, IBDQ, to evaluate and compare the QoL of patients with short bowel syndrome who were on HPN (49 patients: 31 female / 18 male, mean age 45.4 years range 37.7-56.9 years; mean HPN duration 5 years range 0.2-27.8 years; 6 of them also had

large stomal losses), and those who were not on HPN (36 patients: 20 female / 16 male, mean age 50 years range 44.1-64.4 years). These researchers reported that QoL was reduced in HPN patients compared with those not receiving HPN (Jeppesen et al., 1999). In general these findings have raised awareness amongst nutrition support teams who might then be expected to consider the need to assess the impact of HPN on patients' QoL, in addition to their clinical responses to HPN.

Pironi et al. (2004) published their findings of a quantitative study from a specialised centre for management of chronic intestinal failure. They used the non-disease specific short form 36 questiionnaire, SF-36, to assess the QoL in 31 HPN patients with intestinal failure (17 female / 14 male, mean age 45.4 years, range 18-74 years). The mean duration of HPN was 50.4 months (range 2-211 months). The SF-36, a self-administered questionnaire, consists of eight domains: physical functioning, (PF), role functioning physical (RP), body pain (BP), general health (GH), vitality (VT), social functioning (SF), as well as role-functioning emotional (RE) and mental health (MH). These researchers reported that the baseline mean Z-score for 31 patients was reduced in five domains: PF, RP, BP, GH and SF (Pironi et al., 2004). Twenty of the patients again completed the SF-36 questionnaire 10 months later. The Z-score had worsened in eight but improved in 10 patients. The researchers found that the worsened subgroup had a decrease in body mass index, an increase in the number of HPN infusions per week, and a greater incidence of intestinal motility disorders and nocturia. These reported physical symptoms had not been considered in other published studies. Hence, it would be worthwhile to explore these physical symptoms during data analysis of the current small scale qualitative study involving Sheffield HPN patients. The findings would contribute to the generation of theory to aid understanding of the experiences of the patients living with HPN.

All these studies assessed participants against descriptive criteria in a range of standardised questionnaires developed for non-HPN patients. In other

words the researchers made decisions on what information they wanted to ascertain from participants. The use of questionnaires to assess health-related QoL in patients receiving HPN does not support the generation of theory from the data collected, nor does it provide deeper understanding of the participants' experiences living with HPN.

Persoon et al. (2005) published the results of a survey of HPN patients under the care of NSTs based at two Dutch university hospitals. The researchers used two data collection techniques: written questionnaires and structured open-ended interviews. However, there was no explanation for the choice of two data collection methods. 48 HPN patients were sent questionnaires which asked about the extent of problems experienced: fatigue, quality of sleep, anxiety, depression, social impairment and sexual functioning. An open ended interview was carried out in the participant's home. Descriptive analysis of the questionnaire data revealed that the respondents had multiple physical symptoms: severe fatigue (63%), sleeping disorders, (severe) depression (65%), social impairment (55%), and sexual disorders (33%). The respondents reported that these physical symptoms were attributed to their underlying diseases, rather than to HPN. The findings of this Dutch questionnaire were similar to those identified by other researchers, and these have been discussed earlier in the review of published literature. The recorded interview data underwent content analysis by the researchers. They listed the problems in the following categories: psychosocial problems in daily life due to HPN dependence, negative changes in moods and feelings (including anxiety), lack of freedom, limitations in social life and being dependent. Persoon et al. (2005) concluded that HPN dependent patients experienced somatic symptoms which led to primarily psychosocial problems in daily life. These researchers advocated that in order to improve the QoL of patients dependent on HPN, NSTs should assess both somatic and psychosocial aspects of their lives.

Richard et al. (1997) found that some patients receiving HPN, who were already taking opiates and benzodiazepines to control pain and anxiety from their underlying diseases, developed more episodes of catheter-related infection. Other studies found that patients treated with HPN described depression as the most common psychological problem (Carlson et al., 1995). Jeppesen et al. reported that female HPN patients often experienced depression and discouragement, and they appeared more tearful and upset than male patients (Jeppesen et al., 1999). It is becoming evident that HPN can have a significant negative impact on a patient's life style and quality of life (Reddy and Malone, 1998).

In 2005 a systematic review published by Baxter et al. criticised the three types of QoL instruments commonly used for measuring health outcomes in HPN patients (see Table 1) (Baxter et al., 2005)

Table 1 Instruments and methods used to measure quality of life in patients on home parenteral nutrition (Baxter et al., 2005)

Generic instruments	**Disease-specific instruments**	**Non-validated instruments**
Short Form 36 (SF-36) - assesses functioning in eight domains	Inflammatory Bowel Disease Questionnaire (IBDQ)	Time trade-off / category scaling and direct questioning
EuroQoL EQ-5D – a single score on a quality of life scale (0 worse to 100 best)	Quality of Life Inventory	Non-Validated questionnaires
Sickness Impact Profile (SIP)	Quality of Life Index Rotterdam Symptom Checklist	Patient Interviews

Short Form 36 (SF-36) is a generic instrument which assesses eight aspects of life: physical functioning, role functioning-physical, body pain, general health, vitality, social functioning, role functioning, emotional and mental

health. This questionnaire has been validated in different populations but not in patients receiving HPN. EuroQoL EQ-5D has five domains with questions on a range of topics such as self-care, social relationships, pain and mental well-being. It is used in health economic assessment of health related QoL. SIP (Sickness Impact Profile) has 136 items which explore two domains: physical and psychosocial aspects of everyday life. It measures patients' perception of their ability to function, which in turn is used to measure their health status. The SIP has a visual analogue scale and this is used by patients to mark their overall QoL. The authors of this systematic review were concerned with the lack of standardisation in their use for measuring quality of life in health outcomes (Baxter et al. 2005).

Baxter et al. (2005) found that patients receiving HPN continued to have symptoms caused by the underlying disease which had resulted in the need for HPN. They concluded that when assessing patients' QoL, it is important to ask questions that are relevant, pertinent and sensitive to issues that are most important to them. Orrevall et al. (2005) quote from a woman, whose husband had recently begun home parenteral nutrition, to illustrate the need for health researchers to re-think how we should assess the patients' QoL:

> '*You can say that it gives quality of life to the rest of the family and to the patient if you can turn a negative spiral around like this (…) I can only say that I'm happy about the drip, that he gets such energy and strength, and with that comes pleasure and yes, there's certainly a kind of harmony from it*' (Orrevall et al., 2005).

This qualitative study discovered that the most positive aspect of HPN was *'a sense of relief and security that nutritional needs were met'*. It also found that the most negative effect of HPN was related to the *'restrictions in family life and social contacts'*. Both the participants and their family members experienced physical, social and psychological benefits from HPN treatment.

An open interview study in the Netherlands reported that patients receiving HPN experienced negative emotions, physical problems, social limitations, dependence on others, incapability, and patient-care provider problems (Huisman-de Waal et al., 2006). The four open ended questions used in this study were written by the researchers. The study used two interviewers who asked these questions in the same order during each 1 hour interview, which was conducted in the patient's home (Huisman-de Waal et al., 2006). Huisman-de Waal et al. (2006) acknowledged that the small number of questions used in this open interview study provided limited opportunities to explore the issues in detail. They advised that the use of in-depth interviews was necessary in order to confirm their reported findings and to explain the patients' experiences.

A qualitative study using telephone interview of HPN patients and their family carers found that both patients and carers experienced loss of friends, loss of employment and depression (Smith, 1993). Another qualitative study used on-line semi-structured interviews and it discovered six major themes: affirmation of life, infusion-related complications, life-style adaptations, self-worth, isolation, and food intake (Silver, 2004). This provided insights into the daily lives and experiences of HPN patients.

In 2010 Winkler et al. published the findings of a qualitative study which explored the QoL and experiences of living with HPN in adults with IF in the USA (Winkler et al., 2010). The authors discovered that these patients viewed HPN as a life-line and nutritional safety net. Participants in this study defined QoL as enjoying life, being happy, satisfied, or content with life, and being able to do what you want to do, when you want to do it. They described their QoL as good to wonderful and they all wanted normality in life. The authors suggested that qualitative research methodology provides new insights and richness of data from patients treated with HPN. In the same

year, researchers from Scotland published a validated tool, HPN-QoL, to assess the QoL of patients receiving HPN (Baxter et al., 2010). They recommended that this questionnaire should form part of the routine clinical management of patients receiving HPN. However, as far as I know there has been no publication of its use by HPN teams.

2.4.4 Rationale for patient participant in health research

In 2009 ASPEN (American Society of Parenteral and Enteral Nutrition) celebrated the achievements of the United States' first patient, who started HPN in 1973 when she was a teenager. As the world's longest living patient with 35 years of experiences with HPN, she was in full time employment and living independently. Notwithstanding the success of this patient receiving HPN, our understanding of the experiences of patients receiving HPN in the UK remains limited despite the fact that many patients are being offered this ambulatory treatment. The literature review discussed in this chapter highlighted that there were very few published studies of patients' perception of living with this ambulatory treatment in the UK.

A Danish study interviewed 13 HPN patients and 11 partners over a twelve month period using a set of structured questions and quality of life criteria designed by the research team (Ledefeged, 1981). All the HPN patients interviewed had intestinal failure caused by chronic inflammatory bowel disease. The researchers asked about physical symptoms, social and leisure activities, interpersonal relationships, sexuality, psychological problems and feelings about HPN. The study found that forty-six percent or 6 out of 13 HPN participants experienced psychological problems such as depression, irritability and feeling restless. In another Danish study, two questionnaires were sent to 57 HPN and 45 non-HPN patients who were under the care of the national intestinal failure centre in Copenhagen, Denmark (Jeppesen et a., 1999). The two validated quality of life

questionnaires used were: non-disease specific sickness impact profile (SIP) and disease specific inflammatory bowel disease questionnaire (IBDQ). Over 80% of participants completed and returned the questionnaires. The HPN patients reported psychosocial problems with reduced social contacts due to limits on mobility, emotional instability and loss of self-confidence. The researchers concluded that the QoL of HPN patients was reduced in comparison to the non-HPN group or patients with chronic kidney disease dependent on regular dialysis treatment.

A Swedish study examined the QoL and concerns in 28 patients with intestinal failure but only eight of them were on HPN (Carlsson et al., 2003). The researchers used two validated questionnaires: the Short-Form Health Survey (SF-36) to assess the health related QoL and the Rating Form of Inflammatory bowel disease patient concerns (RFIPC) to evaluate concerns identified by participants. HPN patients scored lower for quality of life than those who were not on HPN. HPN patients with a stoma also experienced loneliness, loss of energy levels and reduced sexual drive.

These studies involved small patient cohorts with different validated questionnaires. Therefore, it is unreliable to use these findings to generalise across the spectrum of patients receiving HPN from other countries with different cultural and social traditions as well as different healthcare systems. However, these results highlight the non-clinical issues that mattered most to HPN patients. It remains unclear if patients receiving HPN in the UK experience the same or different psychological and / psychosocial problems. Furthermore, there is a lack of published study on either the QoL or experiences of patients receiving HPN who are under the care of NSTs other than those based at the two national intestinal failure centres.

In 2005 a very different research approach was used by investigators at one of the UK national intestinal failure centres. They examined the illness beliefs of intestinal failure patients on HPN, rather than their quality of life (Fortune et al., 2005). The researchers used the Revised Illness Perception Questionnaire (IPQ-R) to assess the patients' beliefs about their condition and the need for HPN. This questionnaire has been used in other studies of patients with long term health conditions such as chronic fatigue syndrome (Heijmans and de Ridder, 1998), rheumatoid arthritis (Murphy et al., 1999), and irritable bowel syndrome (Rutter and Rutter.2002). Researchers from these earlier studies reported that illness perceptions are useful in predicting psychological wellbeing in patients with chronic illnesses.

This qualitative study conducted by Fortune et al. (2005) involved sixty-one intestinal failure patients on HPN. The researchers found that the participants' emotional representations were unaffected by gender, age when HPN was started, primary diagnosis, presence of a stoma, duration and frequency of HPN feeds. Instead the participants experienced emotional distress from the feeling of a lack of control and a lack of understanding of their illness, and how this led to the need for HPN. These findings contrast with those from previous studies on the QoL of HPN patients which used questionnaires developed and validated for use in patients with other health conditions.

2.4.5 UK experience

In the UK the incidence and prevalence of HPN patients are low in comparison with other chronic illnesses. Advancement in science and pharmaceutical technology has led to improvement in the clinical outcome of patients receiving HPN. They live in local communities and continue to be monitored by NST through attendance at regular out-patient clinics. Since the 1980s there has been increased international research interest to explore

the QoL of life of patients receiving HPN (Ladefoged, 1981, Carlson et al., 1995, Jeppesen et al., 1999, Carlsson et al., 2003).

In 1989 the Nutrition Unit at Salford Royal Hospital (formerly Hope Hospital) published its findings on the effect of HPN on the lifestyle and employment of 30 patients, using a questionnaire designed for the study (Malone, 1989). These researchers found that patients receiving HPN experienced unemployment, sleep disruption and travel limitations and had reduced satisfaction with social and family lives. In 1993 the first UK HPN patient questionnaire survey was carried out by the organisation Patients on Intravenous and Naso-Gastric Nutrition Therapy (PINNT). The survey collected information from members of PINNT about the service from the patients' perspectives (Carter et al., 1993). It reported that most patients were happy with the commercial home healthcare companies, and patients who required the shortest feed infusion time experienced minimal interruptions to daily routines at home.

In 2001 the first BANS report published results from annual questionnaires completed by Nutrition Support Teams (NST) from more than 200 UK centres each year between 1996 and 1999 (Elia et al., 2001). The Nutrition Support Team is a multidisciplinary team which consists of a gastroenterologist and or a chemical pathologist, a nurse, a dietitian and a pharmacist. This was the first time that detailed information on patients' experiences with HPN had been collected by NST. They found that 74% of patients had suffered disrupted sleep during overnight feed infusions. Noise was a problem and 21% of patients found that both the infusion pump and its alarm were too noisy, while 8% found the refrigerator used to store the feed solutions was too noisy. Seventeen percent of patients disliked the inconvenience of having to keep hospital-style infusion equipment at home. Over 60% of them stated that the drip stand, the infusion pump and the stainless steel trolley took up too much space, restricting mobility within the home. Over the

years, technological improvements have led to the use of smaller, portable infusion drip stands and pumps. Today HPN equipment occupies much less space within the home than it did three decades ago.

In summary all the studies reviewed raise questions on the validity and reliability of the methodologies used by earlier studies using questionnaires to provide meaningful insights into the HPN patients' experiences and quality of life. In 2010 Baxter el al. published a validated questionnaire to measure the QoL of HPN patients (Baxter et al., 2010). So far this literature review has not identified any published qualitative studies of adult patients receiving HPN in the UK.

2.5 Aim of this study

To generate theory that explains the experiences of adult patients living with HPN and complex medication regimens.

2.6 Objectives of this study

2.6.1 To analyse patients' experiences living with HPN in order to discover whether or not they have similar social and psychological issues to those reported by researchers in the USA and other European countries;

2.6.2 To explore the implications of the findings for pharmacy practice.

It was intended that the findings would encourage NST to consider not only the nutritional aspects of HPN but also the best way to support patients receiving HPN in the community. Similar research information generated by other NST could be used to compare and benchmark service quality, and to support and promote improvements nationally.

2.7 Chapter summary

HPN is an established treatment modality for patients with malabsorption and malnutrition from chronic IF. Early studies focused on the clinical outcome and complications associated with this treatment. The review of the literature has identified a number of published studies which examined the non-clinical outcome of adults living with HPN. Researchers used different types of instrument and different methods to assess the psychological and social impact of HPN and their QoL (see Table 1). However, these assessment tools, questionnaires, surveys and scales were not validated for patients receiving HPN. Following the publication of a validated tool, HPN-QOL, to assess the QoL of patients receiving HPN (Baxter et al., 2010), I have not come across any published research studies in this patient group using the HPN-QOL questionnaire. This provides a strong rationale for this small scale exploratory qualitative research study with its aim to generate theory about patients' experiences living with HPN. This study offers opportunity for patients receiving HPN to have a voice in such an intervention. The experiences of these patients receiving HPN should be made available to clinical commissioning groups who are responsible for service development in local communities.

Chapter 3 METHODOLOGY AND METHODS

3.1 Introduction to chapter

The literature review described in chapter 2 identified a number of published studies which examined the non-clinical outcome of adults living with HPN. A range of instruments, which had not been validated for patients receiving HPN, were used to assess the psychological and social impact of HPN and the QoL of these patients. The first part of the chapter explains the rationale of patient participant in health research, and the methodology chosen for this study. This is followed by a discussion on the methods chosen for data collection and analysis reflecting the grounded theory approach.

3.2 National agenda and initiatives to encourage patient involvement in health service research

The involvement of patients in research is well established in clinical trials when investigating diseases and developing drug treatment options. Since 2000 there has been an increase in research which focused on clinical effectiveness and patient safety led by the National Patient Safety Agency (NPSA). Over the years there is rising recognition and greater emphasis from the Department of Health to incorporate the experience of patients, their family and friends into the research of healthcare quality.

3.2.1 The King's Fund Report, 'What Matters To Patients? Developing the Evidence Base for Measuring and Improving Patient Experience'

This report, published in November 2011, sets out the future national strategies and approaches for measuring patient experiences (Cornwell and Robert, 2011). The report recommended that Patient Reported Experience Measures (PREMS) should be collected alongside Patient Reported Outcome Measures (PROMS) when assessing quality improvements,

changing local services and reviewing contractual arrangements with providers overseen by CCGs. The report advocates that patients' experience could be collected by direct feedback from patients, service users, carers and wider communities.

3.2.2 The Health Foundation's Evidence Scan No. 18

In June 2013 the Evidence Scan Number 18 published by the Health Foundation provides a comprehensive review of research approaches used to measure patient and carer experiences (The Health Foundation, 2013) The document was compiled following a review of five databases (Medline, Cochrane Library, Embase, Google Scholar and Web of Science) for research studies published in journals in the UK and internationally from 2000 to 2013. Only 328 out of 10,000 published research articles met the inclusion criteria.

The reviewers identified 18 qualitative research studies which used in-depth interviews, either in person or by telephone. They descried the use of telephone interviews with a group of Canadian cancer patients asking them for detailed feedback about their care journey. The grounded theory approach was used to analyse the interview transcripts and it revealed that there was no clear pathway of care. Service managers used the study findings to support the need to make improvement in patient care pathway. The Canadian researchers concluded that the use of conventional questionnaire surveys would not provide this level of discovery. In order to find out patients' experience with a long term health condition, they suggested that it is necessary for clinicians and service providers to understand how these patients live with the illness in their daily life.

This Health Foundation Evidence Scan provides researchers, managers and frontline staff examples of what has been done previously, and gives summaries of the main methods with the potential pros and cons when measuring change over time. This information should be used when planning and deciding what and how to assess patients' experiences with a particular service as well as their perception of service quality.

3.3 Qualitative research methodology

In the past two decades many published studies measured the QoL of patients receiving HPN using a range of questionnaires which were validated for other chronic health conditions (already discussed in chapter 1). Psychological and social issues were reported by a number of quantitative studies, but it remains unclear what influenced their experiences and why they had reported these emotional concerns. It remains uncertain how widespread these issues are amongst patients receiving HPN from different countries.

Studies which used postal questionnaires required respondents to choose an answer from a list of pre-set choices for each question. There were no opportunities for the researcher to ask further questions in order to follow up on an answer along a particular line. These questionnaire studies supported the thematic analysis of issues in the form of facts and opinions which were pertinent to patients living with HPN. The psychological and social issues reported by a number of quantitative studies were underpinned by the objectivist or realist ontology (Creswell, 2013) i.e. facts disclosed by HPN patients also contributed to the objective knowledge. However, we do not understand how and why patients living with HPN experienced these psychological and social concerns. It remains uncertain how widespread these issues are amongst patients receiving HPN from different countries.

In order to understand how and why these psychological and social issues arise, and to elucidate their meanings, there is a need for gathering information from the multiple realities or different perspectives described by the HPN patients. This information or knowledge is underpinned by a subjectivist ontology using an inductive or theory building methodological approach (Creswell, 2013). Corbin and Strauss (2008) advised that the research methodology of a study, including the methods most appropriate for data collection and analysis, is determined by whether or not the aim is to generate theory or to verify existing theory. This would in turn influence the type of data required i.e. numerical data or a description of the participant's feelings, in order to achieve the study aim.

Qualitative research explores the quality and nature of human experiences in a range of social situations in order to understand what these phenomena and events mean to individuals (Draper, 2004). The key focus of qualitative studies are 'what', 'how' and 'why' rather than 'how much' or 'how many'. The study published by Draper (2004) used a qualitative approach so that participants were encouraged to articulate their experiences with HPN and other issues which mattered most to them. The data generated were detailed, rich and complex, giving the opportunity to understand the participants' behaviour and perceptions of this health technology (Pope et al., 2002).

3.4 Methodological approach

Qualitative research explores the quality and nature of human experiences in a range of social situations in order to understand what these phenomena and events mean to individuals (Draper, 2004). The key focus of qualitative studies are what, how and why rather than how much or how many. The research process is one of discovery rather than the testing of hypotheses (Denscombe, 2003). Draper (2004) advised the use of qualitative research

strategy to encourage participants to articulate their experiences with HPN and other issues which mattered most to them. Pope et al. encouraged the use of qualitative research method whereby the data generated were detailed, rich and complex, giving the opportunity to understand the participants' behaviour and perceptions of health technology (Pope et al., 2002).

Quantitative methodology is inappropriate because numerical data could not explain how and why the patients had these experiences living with HPN, and it would not achieve the study aim. I have chosen the qualitative methodology for this study because this approach facilitates the collection of data on the patients' experiences living with HPN, and the generation of theory from this data (Creswell, 2013).

Qualitative studies are conducted under either a constructivism or interpretivism paradigm (Charmaz, 2006, Creswell, 2013). There are a number of theoretical traditions for qualitative research: phenomenology, ethnography, case study, biography and grounded theory. Data may be collected from methods ranging from interviews, observations, and analysis of documents depending on the research questions (Creswell, 2013). Research Interviews are often used to explore why certain behaviours and understandings were displayed and held by specific patient groups.

In terms of the epistemological assumption for this study, semi-structured interviews were conducted by the researcher in order to explore the views and experiences of patients receiving HPN. The researcher makes discoveries of a number of realities or truths based on the construction of that reality from the interview data collected. The findings are unique to a specific setting or situation, so they are not comparable or generalizable with those generated from other situations with different participants. Qualitative

research studies do not make statements of truth on a population basis; but instead they give meanings, perspectives and understandings to individuals' experiences and perceptions without the need to prove accuracy or certainty (Fitzpatrick and Boulton, 1994, Kuper et al., 2008).

This philosophical distinction is important when using a qualitative methodology in this study. This is because the findings would provide a very different perspective to those reported in previous quantitative studies. Furthermore, other qualitative studies on HPN would make unique revelations and discoveries from their participants. This in turn gives NST a deeper understanding on the range of issues that matter most to patients receiving HPN who live in different social settings with diverse culture backgrounds. In some cases the qualitative research findings could be used to extend or modify existing theories already established in other domains.

There is awareness and acceptance that qualitative studies contribute to health service research (Pope and Mays, 1995, Britten et al., 1995). A study of patients' experience with hypertension in primary care shows the value of patient interviews in the discovery of medication adherence in a common chronic health condition (Benson and Britten, 2006).

3.5 Rationale for grounded theory methodology used in this study

The method of data collection for a qualitative study is dependent on the chosen methodological approach taking into consideration the study aims and objectives (Creswell, 2013). When studying patients' experiences with a particular health technology, phenomenology and grounded theory are possible methodological approaches. The other three qualitative research traditions: ethnography, case study and biography, would not support the

collection of the type of data needed to achieve this study's aim of generating theory which explains the experiences of adult patients living with HPN.

Phenomenological study has its focus in identifying and describing the meaning of lived experiences provided by a selected group of participants (Denscombe, 2003). This approach does not lead to the generation of theory about a particular topic. In chapter 2 Literature Review it highlighted that there was a paucity of published information on the experiences of patients' living with HPN in the UK. Grounded theory methodology was chosen for this study to support the generation of theory which explains the experiences of adult patients living with HPN.

3.5.1 The classic grounded theory

Glaser and Strauss (1967) described the original approach to grounded theory methodology, which involved the generation of theory from data grounded in the field involving actions, interactions and social processes of people. They developed a series of steps with the following key features:

- Theoretical sampling (with theoretical saturation) during which the processes of data collection, coding and data analysis are carried out jointly;
- Data collection methods are appropriate for the collection of qualitative data;
- Constant comparative method is used throughout data collection and analysis, including the generation and comparison of analytic codes, as well as the emergence of early categories from data;
- Generating theory from the data;

- Writing of theoretical memos to support all stages of data analysis including coding and identification of categories, themes and the generation of theory.

When Glaser and Strauss stopped working collaboratively, each researcher made modifications to the coding process and used different methods to generate theory from data (Glaser, 1978; Strauss and Corbin, 1990). These led to the development of two types of grounded theory reflecting the different approaches: the Glaserian approach (1978) and the Straussian approach (1990), offering qualitative researchers the choice in data collection and analysis. Over the years other qualitative researchers such as Kathy Charmaz (Charmaz, 2006) made further changes and introduced new analytical processes to the original grounded theory developed by Glaser and Strauss (1967).

3.5.2 Types of grounded theory

With the Glaserian approach (Glaser, 1978) the researcher maintained distance and independence during data collection and the generation of substantive codes during initial coding of data. These codes were used to generate categories through the process of constant comparative analysis. The researcher compared pieces of data within and between datasets, and then generated a number of categories, revealing the properties of each category. As categories were generated, the researcher identified theoretical codes, which linked the categories together, in support of the theory generated from data. Theoretical sampling is crucial as it supports the emerging relationships between categories. The writing of theoretical memos is used throughout the process of coding and analysis in order to explain the researcher's thoughts and to support the processes of decision making when developing the emerging theory. There is a positivistic element in the Glaserian grounded theory approach (Denscombe, 2003).

The approach developed by Strauss and Corbin (1990) retained the principles of data coding and the use of constant comparative analysis throughout the data collection and analysis process. This Straussian approach (Strauss and Corbin, 1990) has the following key features making it a more systematic and interpretative process, in search of the meaning that the data hold:

- Open coding and axial coding to generate categories and to identify relationships between these categories;
- A range of analytic tools which helps the researchers to understand the data during open coding - these analytic tools provided detailed guidance in coding and analysing data when assigning meaning to the information provided by the participants;
- A paradigm model which provides a framework for the researchers to explore the possible relationships between categories during axial coding.

Strauss and Corbin's paradigm model provides a simple and logical approach for qualitative researchers to identify linkages between *'subcategories to a category in a set of relationships denoting causal conditions, phenomenon, context, intervening conditions, actions / interactional strategies, and consequences'* (Strauss and Corbin, 1990 p.99). This paradigm model is a crucial in supporting the integration and selection of categories, and the generation of theory from the data. It provides a framework for new researchers in grounded theory studies to make sense of the data when interpreting the data, and moving towards the development of concepts and the generation of theories systematically (Denscombe, 2003).

The Glaserian approach and the Straussian approach to grounded theory methodology differed in the analytic processes used for data coding, category generation and integration of categories. Qualitative researchers

have to choose which grounded theory approach to follow for data collection and analysis, in qualitative studies. This choice of a methodological approach may be influenced by the supervisor's experiences in qualitative research. This means the supervisor's own experience with a particular grounded theory methodology is taken into consideration when the student chooses a particular grounded theory method for qualitative research. There is an acceptance for researchers to select some elements from both the Glaserian and the Straussian grounded theory approaches, to suit their study design and the researchers' experiences in qualitative data analysis. This has led to publication of grounded theory research studies which deviated from the Glaserian and the Straussian approach (Denscombe, 2003).

In 2008 Kathy Charmaz published her work on grounded theory using a constructivist approach (Charmaz, 2006). She advocated that *'research participants' implicit meanings, experiential views – and researchers' finished grounded theories-are constructions of reality' (Charmaz, 2008 p.10).* Charmaz *(2008)* summarised her constructivist approach to grounded theory with emphasis on the participants' views, values, beliefs, feelings, assumptions, and ideologies rather than on the research methods.

The classic grounded theory requires data to be collected in isolation from any predetermined theory or conceptual framework; and the literature review should be carried out after the data has been collected (Glaser and Strauss, 1967, Charmaz, 2006). This study deviated from the original philosophical construct of the grounded theory approach in that it was necessary for me to conduct a literature review as part of the research proposal submission process to research ethics committee at both local and national level. This information was needed to ensure that research was ethical and worthwhile. A detailed discussion on the ethical and practical issues during data collection is set out under section 3.11 Ethical and practical issues and considerations during data collection.

During the past four decades there has been an increased popularity in the use of qualitative research methodologies for health service research studies. Having considered the different approaches to grounded theory and the methods used to analyse data, I had chosen to follow the analytic framework and to use the paradigm model described by Strauss and Corbin (1990) for this study. I liked the structured approach when using these techniques to support the processes of coding and interrelating categories, as well as the generation of theory based on interview data collected from participants.

This study used semi-structured interviews to explore patients' experiences with HPN. This data collection method was appropriate as it has been used in other health research studies when exploring sensitive issues associated with illness and individual's experiences (Gardner and Chapple, 1999, Carlsson et al., 2001, Notter and Burnard, 2006, Kuziemsky et al., 2007, Kneck et al., 2011). This literature suggests that telephone or on-line interviews do not capture participants' attitudes, beliefs, body language, emotions, feelings or complex interactions with spouse, partner or family members. Focus group with 7 to 10 patients will be difficult to conduct and it is not appropriate for exploring an emotional issue such as HPN. Each participant's experience is unique and it is likely that a group discussion would not give us the high level of individual insight that this study requires. It is only the patients who can inform us how this health technology impacts on their lives.

3.6 Methods of sampling

3.6.1 Participant selection

The Sheffield HPN team also accepts referrals for HPN from other hospitals within the South Yorkshire region. I am not involved with the clinical input to the Sheffield HPN team so participants who were eligible to take part in the

study did not know me during their hospital training for HPN. A small number of patients might have received PN prescribed by me as in-patients at the Northern General Hospital in the past. Once a patient has been accepted for HPN, this patient is transferred to the gastroenterology ward at the Royal Hallamshire Hospital. Therefore, this was not considered to be a cause for bias as the study focus was on their experiences with HPN. I was able to maintain impartiality as researcher when conducting participant selection, recruitment, interviews and analysing the data.

3.6.2 Purposeful and theoretical sampling

The Sheffield HPN team looks after over twenty-five adult HPN patients. Purposeful sampling technique was used to invite these patients to consider participation in the study (Silverman, 2011). This ensured that the study population consisted of participants who would provide an insight into the area being explored. HPN out-patient clinic was held every three month and the gastroenterology department secretary managed all the appointment bookings. This study also received written authorisation from the clinical director of the gastroenterology department who gave me permission to recruit patients at the HPN out-patient clinic (Appendix 9). With permission from the consultant gastroenterologist of the Sheffield HPN team, I contacted the secretary and asked her to send me the HPN clinic list from October 2012 to October 2013. Each clinic list contained the date, time, patient names and their hospital numbers. The list did not contain any clinical details or underlying diagnosis. Once I had received the clinic list, I met with the HPN clinical nurse specialist to identify patients who met the inclusion and exclusion criteria. Purposeful sampling was used to invite participants from the Sheffield HPN clinic to consider taking part in this study. This ensured that participants who met the inclusion criteria were identified and they could contribute to the development of theory in achieving the study aim (Creswell, 2013).

In terms of sample size, it is not necessary to specify how many participants were needed when using the grounded theory methodology. Once early categories had been identified from the data, the use of theoretical sampling ensured that these new participants were appropriate for the study aim and objectives. Theoretical sampling allows further exploration and modification of the theories emerging from the data until theoretical saturation is achieved (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Charmaz, 2006). Strauss and Corbin (1990, p.188) described theoretical saturation is achieved when:

- no new or relevant data seem to emerge regarding a category;
- the category development is dense, insofar as all of the paradigm elements are accounted for, along with variation and process;
- the relationships between categories are well established and validated.

For this study theoretical saturation would be achieved when all the categories emerging from data had been considered in detail, and participants being recruited until no new information emerged during coding and data analysis (Charmaz, 2006). Full details and discussion on data analysis is set out in Chapter 4.

3.6.3 Inclusion criteria

The grounded theory methodology does not require a set of criteria for the process of participant selection (Denscombe, 2003). However, it is desirable to ensure that I have access to individuals who are eligible for the process of purposeful sampling and they are suitable in providing insight into the research topic. Patients who were having HPN feeds alone, home intravenous fluids alone, or a combination of HPN feeds and intravenous fluids, were suitable for consideration to take part. Some patients only

required home intravenous fluids once their underlying conditions have improved, and they were absorbing enough nutrients from food.

3.6.4 Exclusion criteria

Patients who were too ill with impaired consciousness, under the palliative care team for management of symptoms associated with terminal illness or with learning disabilities would be excluded from the study. It was felt that these participants were unable to express their views and experiences independently without the help of carers or family members. With the use of face to face interviews as the only data collection method, it was crucial that participants were able to articulate their views directly without prompts or interpretations by others. Patients with terminal illness were excluded as their underlying life-limiting condition imposed different constrains on their experiences with HPN (Orrevall et al., 2005). Furthermore, their life expectancy was such that it was difficult to manage with the use of constant comparative analysis within the time frame of up to two years allocated for this study.

3.6.5 Invitation letter

I prepared a standard 'Invitation letter' to explain the purpose of the study and why we wanted to find out about their views and experiences with HPN, and how and where the study interviews would be carried out (Appendix 4). It advised the patient to refer to the 'Participant information sheet' for more details. The wordings used were checked for readability to ensure the information was clear and easy to understand by a member of the general public. My name and contact details were included so that patients could contact me if they have other questions before their next clinic appointment.

This information ensured that patients were well informed of their involvement when considering participation in healthcare research. The invitation letter and the information sheet about the study were prepared as part of the research proposal, which was submitted to the local ethics committee at the Sheffield Teaching Hospitals NHS Foundation Trust's Research Department.

3.6.6 Information about the study

I used the template provided by the Integrated Research Application System (IRAS) to prepare the 'Participant information sheet for competent adults', and it contained the following information (Appendix 5):

- The purpose of the study;
- What information was being collected from them;
- How and where the research interviews would be conducted;
- How the data would be recorded and transcribed;
- How the transcripts would be discussed and shared;
- How patient confidentiality and anonymity would be protected;
- How the findings would be reported and published;
- How the study materials would be stored securely and then destroyed after publication of the report.

It also had the study number issued by the Research Department at Sheffield Teaching Hospitals NHS Foundation Trust (STH 16314), and by the National Research Ethics Service (NRES) Committee North West – Greater Manchester North (REC reference number 12/NW/0554).

3.6.7 Information pack

From September 2012 to September 2013, an 'Information pack' containing the following documents was set up:

- Invitation letter
- Participant information sheet
- Consent form

I prepared each document in a pdf format, and these files were sent electronically to the gastroenterology department secretary. The secretary printed these documents using hospital headed stationery. She posted an 'Information pack' and the HPN out-patient clinic appointment letter to patients who had been identified by me as meeting the inclusion criteria during purposeful sampling. This ensured that the patient's address was not disclosed until he or she had given written consent to take part in the study. Patients and their family had time to read the materials and ask me questions at the HPN out-patients clinic.

3.6.8 Participant recruitment

I designed a recruitment poster to advertise the study (Appendix 3). The poster was on display at the RHH out-patients clinic from September 2012 to September 2013. It was intended to raise interest and awareness among HPN patients as part of the recruitment strategy. This approach reflected the principles of INVOLVE, an advisory group established by the National Institute for Health Research in 1996. Its role is to bring to together expertise, insight and experience in the field of public involvement in healthcare research.

I attended the HPN out-patient clinics from October 2012 to October 2013. I had a list of HPN patients who met the inclusion criteria and used this to support the principles of purposeful sampling (Glaser and Strauss, 1967). I had the opportunities to speak to prospective patients who had been sent the 'Information pack'. It was helpful for me to meet them face to face giving them reassurance about their involvement, and how this would not influence

or prejudice their clinical management by the Sheffield HPN team during subsequent clinic visits.

A small number of patients declined to take part. I accepted their decisions and did not ask them any further questions because they were under no obligation to take part in health service research studies. I respected their right to decline the invitation without giving reasons or justifications. As a researcher I recognised my ethical obligation to respect participants' decisions in relation to consent. This was supported by the participant information sheet for competent adults (Appendix 5) – part one, the question on 'Do I have to take part?'; and the participant consent form question 2 (Appendix 6).

I did not specify the total number of participants to recruit or to interview for this study. This is because the use of the grounded theory approach with theoretical sampling and constant comparative analysis ensures that the interview-analysis process continues until clear and consistent patterns appear in the generation of codes, categories, concepts and theories (Glaser and Strauss, 1967, Corbin and Strauss, 2008). Health service research using the grounded theory approach to analyse interview data usually involves between ten to twenty participants. Therefore, it was decided that I would interview approximately 50% of the twenty-five HPN patients and this would be achievable within the two years allocated for this study.

3.6.9 Consent form

The questions used on this form to ascertain informed consent were those set out in the IRAS guidance notes on Participant consent form (Appendix 6). A copy of the consent form was included in the Information pack so that patients were made aware of the contents of this document in advance. A

more detailed explanation is provided under the section 3.11 Ethical and practical issues and considerations during data collection.

There was a discrepancy in the notification of the participant's general practitioner in the Participant information sheet competent adults (Appendix 5 Part Two) and the statement number 4 on the Participant consent form (see Appendix 6). This had been addressed by the researcher when she met with the each participant to obtain written consent. The researcher discarded the statement number 4 on the Participant consent form (Appendix 6). The researcher also documented this omission on the consent form. The participants were reassured by the researcher that the general practitioners or other healthcare professional would not be notified of their participation in this research study.

3.7 Methods of data collection

3.7.1 Research interviews

Unlike conversation which occurs in everyday human interactions, research interviews are conversations with a structure and a purpose (Denscombe, 2003). An interview is literally an *inter view*, an inter change of views between persons conversing about a theme of mutual interest (Kvale, 1996 p. 2). In the context of health service research, there has been a rise in the use of qualitative interviews to achieve deeper understanding of the social world in relation to patients' perception of a health condition (Johnston et al., 2007) or their experiences with a healthcare service (Munday et al., 2009). Interviews allow participants to express their points of view in their own words and to tell us their perceptions and meanings of their lived world (Kvale, 1996 p. 11). Through interpretation and inductive analysis of the interview transcripts, researchers make discovery of how individuals live with a chronic health condition in specific social settings (Fitzpatrick and Boulton, 1994).

Interview is an acceptable data collection method for grounded theory studies (Charmaz, 2006, Creswell, 2013), when exploring human interactions with focus on a particular setting. Charmaz (2006) describes the use of either in-depth or semi-structured interviews. The use of some open ended questions, along with probing questions, ensures that the participants do not deviate away from the study aim. During the process of theoretical sampling, the interviews became more semi-structured in order to explore emerging themes and categories, which illustrated patterns of similarities and differences.

For this study the use of semi-structured interviews provided the researcher with the opportunity to be flexible in letting participants develop ideas to speak openly on the issues which illustrated the themes of the lived daily world from their own perspectives (Kvale, 2007). Semi-structured interviews were more appropriate than in-depth interviews in meeting the study aim, which involved the generation of theory to explain the experiences of participants living with HPN rather than developing a detailed knowledge about one or two aspects of this health technology (Britten, 1995).

3.7.2 Preparation of interview guide

The topic of qualitative research interviews is the participant's lived everyday world (Kvale, 2007). It is uncommon for a researcher to carry out a research interview without some ideas in mind on the sort of questions to ask the participant. I developed a semi-structured interview guide (Appendix 7) using published guidance, advice and information from a number of reference sources: interview questions used by other researchers in this field (Silver, 2004, Huisman-de Waal et al., 2006, Emedo et al., 2010). When preparing the semi-structured interview, I ensured that the questions were phrased so that they were open-ended reflecting the topics which would be asked to all

participants. The first question was phrased so that it was general but specific and served as an introduction to the purpose of the study:

'Tell me about how you came to receive home parenteral nutrition?'

Each question was not asked in a specific sequence so that it encouraged participants to articulate their views, thoughts and experiences spontaneously and naturally without making the process too structured and prescriptive (Kvale, 1996 p.126-135). I also took into account some general advice on interview questions (Keats, 2000 p.75):

Will the questions mean the same to all participants?

Is the vocabulary appropriate?

Will the phrasing be easily understood?

How long would it take to go through these during the one-hour interview?

Is there any bias in the content or in the way the questions are phrased?

In order to ensure that the questions were valid and appropriate for this study, I took a closer examination and comparison of the interview questions used by other researchers in studies with HPN patients (Silver, 2004, Huisman-de Waal et al., 2006, Emedo et al., 2010, Winkler et al., 2010). The study aims were different but they provided me with ideas on what sort of questions to include in the interview guide. For questions on diet and medications, I developed these using personal experiences as NMP when counselling patients who were on PN and taking these diets and drugs to slow down fluid losses from ileostomies. I did not access the participants' medical records. The comments on medicines arose as part of the interview process.

In contrast to interview questionnaires, I did not ask each participant all the questions in the semi-structured interview guide. During each one hour interview the researcher demonstrated flexibility by making decisions on which open-ended questions to ask and the questions could be re-phrased in order to explore topics or issues raised by the participants during the interview (Kvale, 2007). Once I had transcribed and coded an interview, these codes were analysed to support the emerging categories. With each participant I followed the line of questioning underpinned by the joint processes of data collection and analysis. The semi-structured interview guide supported the process of theoretical sampling as early themes and categories were emerging. The questions were modified after the first two interviews (Appendix 8).

I included some follow-up probes to guide the conversations with participants in case they were nervous, or if they digressed from the study objectives. The semi-structured interview guide was discussed with other NST members and they agreed that it captured important and relevant information related to patient experience.

3.7.3 Interview recording

I used a hand-held portable dictaphone with computer connection to record the interviews. Each participant was allocated a numerical number starting from P#1, 2, 3, 4, etc. This number was important in linking the participant to the audio-tape recording, the typed transcript and the hand written notes made during the interview. These steps were important to maintain study integrity and data traceability. The participant's name and other identifiable information were omitted during the interview in order to maintain anonymity. There were occasions when I had to suspend the interview recording for a brief moment in order to give the participants a few moments to recover from emotional outbursts or upsets. A brief description of these situations was

included in the transcript in order to capture these moments. This level of accuracy was important to maintain trustworthiness of the transcription process reflecting the participants' range of emotions which were not easily described in words by the individuals (Kvale, 2007) or transcribed by the researcher.

3.7.4 Written notes during each interview

During each interview I kept written notes to capture observations made in the participant's home. I found this helpful as it allowed me to hear, see and experience reality that the participants and their family members did. I used these notes to identify new ideas, to create a 'big picture' and to compare observations made at subsequent interviews. This level of immersion gave me the opportunity to learn directly from the participants and to gain understanding and insight of differing perspectives in their natural settings (Marshall and Rossman, 1999). It was crucial for me to become sensitised to the participants' life stories, so that I could incorporate a holistic approach during open-coding and induction analysis of the themes, categories and concepts.

3.7.5 Interview transcriptions

This small scale exploratory study did not have any financial resources to pay for an audio-typist to transcribe. After each interview I transcribed verbatim from the audio-tape before the next interview was conducted. The sound quality of the tape was acceptable so it did not affect the accuracy of the text. Kvale commented that transcripts are decontextualized conversations (Kvale, 2007). When transcribing verbatim it was important that I typed every word in exactly the way that it was being said without correcting or tidying up the sentences to make them read scholarly. In everyday conversations, people do not speak in neatly constructed sentences (Denscombe, 2003). When

transcribing I listened to what the participant was saying as well as capturing verbal cues such as pauses, sighs and laughters reflecting the participant's emotion as well as speech style.

3.7.6 Strategies of analysis

The research area for this small scale, exploratory study is focused on the views and experiences of HPN patients. With no previous established theory for the social phenomenon, there is a strong sense of discovery from patients who are living with this health technology. This simultaneous approach of interviewing, transcribing and coding the transcript is important in demonstrating constant comparative analysis, which is characteristic of the classic grounded theory methodology (Glaser and Strauss, 1967). These meticulous processes and the emphasis on the researcher's theoretical sensitivity were considered to be relevant to this exploratory study. Glaser and Strauss proposed that *'the researcher's theoretical sensitivity is crucial when conceptualising and formulating a theory as it emerges from data'* (Glaser and Strauss, 1967 p.46). It was important that I demonstrated the ability to understand what is going on with the data, what is relevant and what is not, as well as having insight when giving meaning to data during simultaneous data collection and analysis. I have taken these into account in the development of the strategies of analysis.

Strauss and Corbin worked collaboratively developing their version of the grounded theory with new interpretations and approaches to data analysis (Strauss and Corbin, 1990). Their analytic approaches evolved both in the methodology and the methods used for building theory (Strauss and Corbin, 1998). They used diagrams as well as memos to illustrate possible relationships between concepts in the generation of theory (Corbin and Strauss, 2008). As a novice researcher I found the use of diagrams helpful in

conceptualising the participants' stories during the processes of open coding with interview transcripts.

Charmaz presented a different interpretation to this classic grounded theory. In her book, *'Constructing grounded theory'*, she described her grounded theory methods as, *'a set of principles and practices, not as prescriptions or packages' (Charmaz, 2006 p.9).* She maintained that *'the research participants' meanings, views and the researchers' finished grounded theories are constructions of reality' (Charmaz, 2006 p.10)*. These remarks are highly relevant to this study with participants providing views, experiences and insights of their *'world'* living with stoma care and HPN treatment. Charmaz' pragmatic approaches to data analysis have influenced my strategies of analysis supporting the need to *'construct'* the reality described by the participants.

3.7.7 Analytic tools

Analytic tools are devices and techniques used to facilitate the coding process (Strauss and Corbin, 1998 p.87). The interview transcripts of this study contained stories of events, issues and responses which were closely integrated into the participants' daily lives. The similarities, differences and relationships emerged from the data, were explored in subsequent interviews with the use of theoretical sampling (Charmaz, 2006). Having read and coded the transcription before the next interview, the researcher could identify any factors that might introduce bias to the interview or coding process. The researcher would take into account steps needed to minimise the biases identified in subsequent interviews and coding of transcriptions.

In order to gain awareness and understanding of these descriptions, I used a combination of analytic tools developed by grounded theorists to code data

(Charmaz, 2006, Corbin and Strauss, 2008). Table 2 provides a summary of the analytic prompts used for opening coding, and to make comparison for similarities and differences within and between datasets.

Table 2 Analytic prompts for open coding

Remain open. Stay close to the data. Keep your codes simple and precise. Construct short codes. Preserve actions. Compare data with data. Move quickly through the data. (Charmaz, 2006 p.49-50)	Who, what, when, where, how and with what consequence. Frequency, duration, rate and timing What is going in here? (issues, problems, concerns) What is the relationship of one concept to another? (how do they compare and related at the property and dimensional level) Which concepts are well developed and which are not? Where, when, and how to gather data for the evolving theory? (Corbin and Strauss, 2008 p.71-72)

I used these prompts to discover meanings, concepts, emergent categories and their properties and dimensions during open coding and the writing of theoretical memos. The analytic plan and the processes used in this study followed the principles of constant comparison analysis with data collection and coding being carried out jointly with data analysis. The following sections describe in detail the analytic plan and analytic processes with the use of theoretical memos.

3.7.8 Analytic plan

The interview transcripts were dense in text with the participants' narratives on their views and experiences living with stoma and HPN. The analytic plan

consists of open coding, development of concepts, themes and early categories through analysis. These steps were carried out jointly alongside data collection following the principles of constant comparative analysis (Glaser and Strauss, 1967).

Open coding has always been done by hand but since the 1980s specialist computer assisted qualitative data analysis software (CAQDAS) has become popular. Computer programmes reduce the time spent in sorting, locating and managing codes in large scale studies e.g. MAXQDA and N-Vivo. These programmes provide an audit trail of the analytic processes (Denzin and Lincoln, 1998). Some researchers were concerned with the stifling effect on analytic creativity making the process mechanical (Fielding and Fielding, 1986). Others suggested that computer programmes would direct the analytic processes in structuring the analysis (Creswell, 2013).

Researchers have to learn how to operate these programmes first which takes time (Creswell, 2013). Corbin and Strauss recognised the value of computer programmes in helping the analysts to see *'flaws in the logic, undeveloped categories, and insufficient conceptualisation'* when the data is presented visually to them during early stage of analysis. This could improve the analysts' techniques in coding and data analysis (Corbin and Strauss, 2008 p.310).

Having considered these factors and the limited time available for this small scale, exploratory study, I decided to analyse the data by hand instead. The concepts generated from the transcripts represented my impression, understanding and interpretation of the participants' described experiences, their spoken words, actions, interactions, problems and issues. I gained confidence in coding, identification of concepts and the generation of

categories. This approach allowed me to be immersed in all stages of data analysis, and to develop theoretical sensitivity in understanding and interpreting the data. These experiences were crucial in helping me to incorporate theoretical sampling during joint data analysis and collection as the study progressed. These key elements are central to the analytic plan reflecting the classic grounded theory approach (Glaser and Strauss, 1967 p. 45-47).

For the analytic plan of this study I followed the advice and techniques from Charmaz (Charmaz, 2006) and from Corbin and Strauss (Corbin and Strauss, 2008). These techniques provided me the framework when starting the process of open coding using a range of techniques. Theoretical memos were then used to identify themes, to refine concepts and categories during constant comparison within and between datasets, to make improvements to the interview guide during theoretical sampling, and to generate theory.

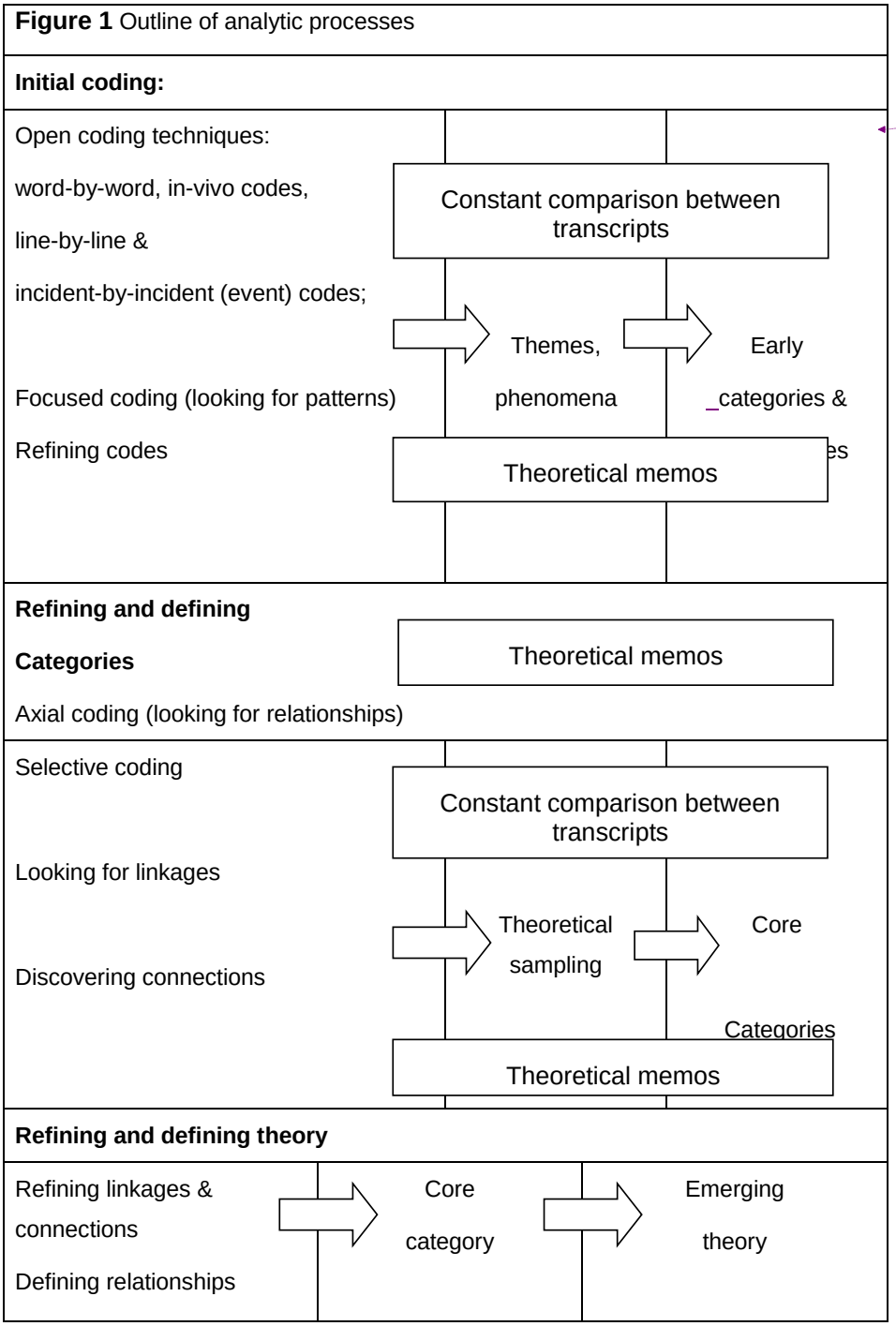
3.7.9 Analytic processes

The first stage in open coding of data is to identify concepts which would be used as *'building blocks of theory'* (Strauss and Corbin, 1998 p.13). This study used a semi-structured interview approach for data collection. During each interview the flow of conversation was led by the participant with guidance provided by the researcher using an interview guide. Having transcribed the first interview verbatim, my initial impression from the transcript P#1 was that it was full of narratives on incidents, events, issues and reactions which revolved around the stoma and HPN in the participant's life at home and in social situations.

Jeppesen et al. (1999) and Carlsson et al. (2003) reported a lower QoL for HPN patients with stomas. However, it was unclear the extent of the impact

both HPN and stoma have on the participants' lives. Other published questionnaire studies which measured the QoL of patients receiving HPN using Short Form 36 (SF_36), Euro-QoL EQ-5D or Sickness Impact Profile (SIP), did not have information on the participants' experiences with stoma and having HPN. The interview transcript provided detailed contextual information on how the participant integrated HPN as well as stoma care in everyday life at home and in social situations. Figure 1 provides an outline of the analytic processes used in this study. Details on open coding techniques are described in Section 3.7.9.1 Open coding techniques used to label transcript segments. The focus of the initial literature review was HPN. As a consequence of developing theory, stoma started to emerge as a common feature amongst the participants.

Figure 1 Outline of analytic processes



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3.7.9.1 Open coding techniques used to label transcript segments

Each interview recording tape was transcribed verbatim). The data segments are coded in two main stages in grounded theory studies. Coding is a dynamic process providing the essential link between collecting data and developing an emergent theory grounded in these data (Charmaz, 2006).

The process of open coding is the first step to analyse data that has been collected during a face-to-face, semi-structured interview before collecting more data. This initial coding stage involves the naming or labelling of each word, line (Strauss and Corbin, 1998), incident (or event) (Charmaz, 2006) or segment of data and the identification of in-vivo codes (Glaser and Strauss, 1967) to reflect actions and interactions.

3.7.9.2 Focused coding, axial coding and selective coding techniques

This second stage involves the use of focused coding and axial coding to sort, interpret, integrate and organise large number of codes into the most salient categories (Strauss and Corbin, 1998, Charmaz, 2006, Corbin and Strauss, 2008). This latter stage also supports the theoretical integration of focused codes during the process of axial and selective coding in order to refine categories.

I also used the questions described by Corbin and Strauss to start the open coding process with transcript P#1 (see Table 2 Analytic prompts for coding). The interview transcript was condensed by assigning a short phrase to reflect a process, an action, and interaction in the data (Corbin and Strauss, 2008). The analytic prompts were also used to stay open minded with the participant's narratives (Charmaz, 2006). These analytic prompts were used throughout this study to facilitate coding, data analysis, development and generation of core theory.

3.8 Quality criteria for research interview

When using research interview as a method of data collection, the interview itself is neither an open conversation nor a highly structured questionnaire (Kvale, 1996 p.27). There is an acceptance that the researcher determines how closely to follow the semi-structured interview guide during the actual interview. Kvale described the importance of addressing the issue of quality in interview research in relation to the characteristics of the researcher and the interviewees (Kvale, 1996 p.145-151).

This study recruited HPN patients who came from a diverse social and clinical background. After the first few interviews I noticed that they displayed varying level of the good interviewees characteristics (Kvale, 1996): coherent, eloquent, motivated and knowledgeable. I believed that this was a reflection of the participant's own experiences. Being mindful of these variations, I ensured that I maintained a sense of balance when guiding the conversations and encouraging the participants to express their views, beliefs and perceptions freely in their own words.

During the interview I was flexible in following up on the participant's response in order to pursue interesting revelations and delve deeper into the meanings of the disclosures (Fitzpatrick and Boulton, 1994). In some instances the questions in the interview guide did not fit in with the flow of the conversation or relate to new subjects raised by participants. After the first few interviews, I modified some of the questions in order to maintain reliability when using these in subsequent interviews (DiCicco-Bloom and Crabtree, 2006) (Appendix 8). This modified interview guide (Appendix 8) supported the process of theoretical sampling of participants. With the early categories and subcategories identified, subsequent participants were selected for interview in order to explore the linkages and connections in these early categories and subcategories.

The option to carry out pilot interviews was considered, and it would require a separate application to be made for ethical approval by the hospital's Research Ethics Committee because of the need to involve patients. The Sheffield HPN team looks after a small number of patients. I was uncertain how many patients would give written consent to take part in pilot interviews. Those patients who had taken part in pilot interviews would be excluded from recruitment for the study. Following discussion with my academic supervisors, it was agreed that the patient numbers were too small for carrying out pilot interviews. Furthermore, the limited timescale for this study meant that it was unachievable to conduct pilot interviews prior to starting the study.

There are no standard procedures for interview research. However, it is important that I maintained neutrality and consistency during interviewing, transcribing and data analysis (Kvale, 1996 , Keats, 2000). For this study I was responsible for interviewing all the participants, so it was important that I demonstrated reliability throughout the process by asking the questions consistently with the same meaning to each participant. I started each interview in the same way with general opening statements. I had to ensure that each interview would last up to one hour. However, there were occasions when interviews ran overtime because these participants had complex issues to disclose and these were relevant to the study objectives and important to the emerging concepts.

With participants coming from a diverse demographic, social and clinical background, I ensured that they felt safe and comfortable during the interview (Creswell, 2013). Interviews for health service research are often carried out in natural or social settings which are familiar to the participants. For this study I chose to conduct interviews at the participants' home. I offered to interview them at the hospital if they preferred this instead. All participants were happy to be interviewed at home. It was important that I established

rapport and trust with each participant at the beginning of an interview. I did this by expressing of my gratitude and respect for their contributions to the study (Kvale, 1996 p.125, DiCicco-Bloom and Crabtree, 2006 p.316). In health service research which involves a sensitive topic, some participants might make unexpected revelations as they recalled past personal experiences and emotions. I approached each interview with an open mind and anticipated that each individual would respond differently to the same questions reflecting their individualities and circumstances.

I was mindful that the interview did not become a therapeutic situation or clinical consultation. If this happened I would remind the participant that this information disclosed would be excluded from analysis. I would advise the participant to consider seeking medical advice if the situation was deemed serious or had clinical significance following discussion with the individual. It was important that I recognised these situations promptly and steered the participant back to the interview focus with being perceived as abrupt, insensitive or judgemental.

As a registered pharmacist it is important that I follow the professional and ethical codes of practice during clinical and research activities. Within the interview context if I came upon any information that the participant required with HPN administration, I would interrupt the interview process and explain to the participant the cause of my concern. I would advise the participant to contact the clinical nurse specialist of the Sheffield HPN team for further information and training support. My duties of care were maintained throughout all the interviews in order to ensure safety of participants and confidentiality of the individuals.

The experience from carrying out research interviews gave me a high level of sensitivity and closeness to the HPN patients' lives, and the reasons and motivations for their attitudes and factors which influenced these. As the sole

researcher for carrying the interviews, this approach minimised the possibility of variations associated with multiple interviewers.

3.9 Trustworthiness

In qualitative research interviews, trustworthiness is used to describe the quality of the interviewing itself (Kvale, 1996 p.237 Box 12.1). I demonstrated trustworthiness by ensuring that the questions included in the interview guide were relevant without imposing personal bias or the use of closed or leading questions (Kvale, 1996). Kvale (2007) highlighted the potential impact of the interview process on the participants because of the complexities of 'researching private lives' and the publishing of study findings which could be accessed openly in the public arena (Kvale, 2007 p.23).

With no previous clinical contacts with these individuals, I was unknown to them so I was able to encourage participants to articulate their feelings, emotions and experiences freely during the interviews with gentle probing for elaboration when necessary. It was important that I was sensitised to the issues raised by the participants, but without over-familiarity with the participants which could affect the validity of the interview data (Creswell, 2009). I was able to maintain the rigor of the data by being resourceful, systematic and honest in uncovering and describing the participants' experiences and perspectives on HPN when recording the interviews, preparing the transcripts and analysing the data (Marshall and Rossman, 1999).

3.10 Research ethics committee approvals

This research study proposal was approved by the hospital's Research Department for consideration in October 2011(STH number 16314). This was then submitted to the NHS National Research Ethics Service (NRES) for

proportionate review by the REC Sub Committee. Approval from the NRES Committee North West – Greater Manchester North, Proportionate Review Sub Committee was received in August 2012 (REC reference 12/NW/0554).

3.11 Ethical and practical issues and considerations during data collection

3.11.1 Interview environment

Some participants might feel nervous about being interviewed by a researcher. Therefore, I carried out each interview during normal office hours so that it caused least disruptions to the participant's daily routine. I also ensured that it did not clash with the HPN delivery schedule. On arrival at the participant's home, I made a brief introduction of myself and the purpose of the study. It was necessary to remind the participant as there was usually a gap of several months since I obtained written consent for the interview. I also asked the participant to choose where in the house to have the interview. It was important that the individual felt comfortable during the one hour interview (Denscombe, 2003). I asked the participant if he or she would prefer to have the spouse, partner or other family members present during the interview. I explained that family members were welcomed to observe the interview but they would be discouraged from taking part with the conversation. All study participants were happy to be interviewed alone.

3.11.2 Recording process

In order to ensure the individual was at ease, I explained how the portable dictaphone worked and the red light would stay on during recording. I placed the dictaphone within easy reach by me and the participant, so either of us could push the pause button at any time. This gave me and the participant control over the recording process if more time was needed before responding to a particular question. The participant's name and other

identifiable information were omitted during the interview in order to maintain anonymity. Some participants might feel nervous about having an interview recorded. I would play back the audio-tape at the participants' request if they felt what the said did not reflect their real feelings, or there were not expressed accurately in the way they intended (Oliver, 2004). This was important in demonstrating trustworthiness of the interview data provided by the participants (Kvale, 2007).

Before the start of each interview, I explained to the participant that he or she could stop the recording session at any time after it had started. When this happened I would ask the participant if he or she no longer wished to continue with the study. If so, the information already recorded would not be used in the data analysis. I would destroy the audio-tape and any written notes in accordance with the hospital's policy and the NRES guidance on disposal of confidential information.

There were no participants who changed their minds during the interview stage. However, a few participants did change their minds after they had given written consent but before we agreed on a date and time for the interview. I had to stop the recording several times with some interviews. This was because few participants were becoming emotional and tearful when they were recalling and describing their experiences with their illness.

3.11.3 Participant interview log

I used this to record the participant number (e.g. P#1, 2, 3, 4 etc.), name initials, contact details (home address and telephone number), interview date & time and confirmation of arrival and departure times (Appendix 10). This log was incorporated in the 'Investigator Site Master File' for this study as specified by the hospital's Research Department. I saved this log as a

Microsoft Word document on the pharmacy department's server within the hospital's computer network. I was the only person who had access to this file which was restricted and protected by username and password in accordance with the hospital's policy on data protection. This log also served as an audit trail which confirmed when, where and how many interview data were collected. All these steps were necessary in order to maintain secure storage of research data in compliance with the hospital's Research Department policy on protection of patient data.

3.11.4 Interview schedule

I notified the pharmacy department's secretary every time I interviewed a participant. This was done by printing a copy of the 'Participant interview log' with the participant number, initials, telephone contact number, address, interview date and time. I telephoned the department's secretary to confirm time of arrival and departure from the participant's home. These steps were necessary in order to meet the hospital's 'Lone Worker Policy'. I updated the electronic copy after each interview and the paper copy was discarded as confidential waste.

Some participants might feel nervous about having an interview recorded. I would play back the audio-tape at the participants' request if they felt what the said did not reflect their real feelings, or there were not expressed accurately in the way they intended (Oliver, 2004 p.46). This was important in demonstrating trustworthiness of the interview data provided by the participants (Kvale, 2007).

In order to maintain trustworthiness when transcribing speech to text, it was important that I did not mishear or misinterpret what the participant has said due to the individual's speech style, accent, dialect or poor clarity of the

recorded passages (Denscombe, 2003). This process of listening to the tape, reading and checking with the transcript had given me the opportunity to become familiar with the data and sensitised to the issues being disclosed.

Although transcribing was time consuming, it brought me *'close to the data'* by listening to the conversations again (Denscombe, 2003 p.183).

> '*Transcribing involves translating from an oral language, with its own set of rules, to a written language with another set of rules' (Kvale, 2007 p.98)*

This level of data immersion was helpful in the generation of categories during the early stages of data collection. This transcript was analysed using the technique of open-coding. The processes of data collection and data analysis were carried out jointly demonstrating the principles of the grounded theory methodology (Glaser and Strauss, 1967). I developed theoretical sensitivity to the relationships being revealed between emerging categories with open codes generated from each subsequent transcript (Strauss and Corbin, 1998, Charmaz, 2006). I captured these thoughts and ideas on similarities, differences and connections between the open codes with the writing of theoretical memos (Charmaz, 2006). I had written theoretical memos and used these to guide me in the process of axial coding and selective coding, as well as during joint data collection and open coding. A full discussion of these analytic processes is described in chapter 4.

3.11.5 Transcription format

There are established conventions on the style and syntax for presenting interview transcriptions (Denscombe, 2003). Silverman developed a list of standardised transcription symbols for annotation of the participant's

gestures, uncomfortable silences or other feelings which can enrich the meanings of the spoken words (Silverman, 2011 p.465-466). For this small scale study I adopted some of the conventional symbols described by Silverman (Silverman, 2011). Verbal tics such as 'er', 'um', and 'erm' were omitted in the transcripts because they did not make meaningful contributions to the issues being described by the participants (Kvale, 2007 p.95). However, I had included others such as 'like', 'you know what I mean' and 'sort of' to reflect and capture the participants' emotions and feelings (Kvale, 2007). It was necessary to preserve these as much as possible in the transcripts without any attempts to tidy up the speech.

If there were occasions when the participants needed a few moments to recover from emotional outbursts or upsets, I would suspend the interview recording. A brief description of these situations would be included in the transcript in order to capture these moments. This level of accuracy was important to maintain trustworthiness of the transcription process reflecting the participants' range of emotions which would not be described in words by the individuals (Kvale, 2007) or transcribed by the researcher.

3.12 Limitations of interviews

This study used research interviews with a small number of adult patients receiving HPN, and the grounded theory approach to analyse their experiences. The experience of the researcher in conducting interviews may influence the quality of the data recorded during an interview (Kvale, 2007). Kvale proposed that 'one does not become a good interviewer through reading a book about interviews' (Kvale, 2007 p.137). There were a number of limitations to this study.

Although the interview guide for this study contained all the relevant questions to ask the participants, I found it distracting when glancing at the guide and trying to listen to what the participant was saying at the same time. When I was transcribing the first interview verbatim, I recognised the awkwardness in the dialogue between the participant and me (Kvale, 2007). There were lost opportunities in asking follow up questions when an unexpected topic was raised by the individual. Having listened to the first one-hour audio-tape, it had given me the opportunity to make improvement in the interview technique with subsequent interviews and a few of the questions in the guide. I more confident and less anxious after the third interview as I became sensitised to the range of issues these participants were describing during the interviews.

Patients receiving HPN under the care of the Sheffield HPN team were considered for recruitment. The use of purposeful sampling strategy and theoretical sampling ensured that these participants were appropriate for the study aims and research question objectives.

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3.13 Limitations of the study design

The limitations of the study design will be discussed covering a number of issues: interview guide, sample size, generalizability of finding, respondent validation and researcher's subjectivity and experience.

A weakness of this study was the lack of opportunity to pre-test the questions included in the interview guide. As categories and subcategories were emerging during data analysis, the interview guide was changed in support of the theory development using the grounded theory methodology. The limited timescale of this study would not support a new application for approval from

the hospital's research ethics committee so that the researcher could test the suitability of the questions with patients receiving HPN.

The option to pre-test the questions used in the interview guide with patients treated with HPN would ensure that the wording of the questions was appropriate without causing distress, worry or annoyance to the participants; the level of information to be collected from the participants was relevant in meeting the study aim; and the phrasing of the questions was clear without ambiguity or bias (Denscombe, 2003). This would mean that these patients would have to be excluded from the study recruitment process. There were only twenty-five patients receiving HPN under the care of the local nutrition support team. Therefore, it was impracticable to pre-test the interview guide as this would reduce the number of available participants who would be assessed against the inclusion criteria for this small scale exploratory study.

In order to overcome this issue, the interview guide contained questions which had been compiled from published qualitative studies which involved patients receiving HPN (Silver, 2004, Kvale, 2007, Winkler et al., 2010) (see Appendix 7). The researcher reviewed the original publication of each of these studies, and was satisfied that these questions which had been selected for use in the interview guide were appropriate for this study. This approach ensured that the questions were relevant to patients receiving HPN. During the joint processes of data collection and data analysis, the researcher had made changes to the questions in the interview guide in order to reflect the development and refinement of the emerging categories and subcategories. This revised interview guide was used in subsequent data collection (see Appendix 8).

The notion of sample size in grounded theory studies had limited relevance in the context of supporting theoretical saturation during joint data collection

and data analysis (Corbin and Strauss, 2008 p.148-150). All prospective participants of this study were purposefully selected whereby they were under the care of the local nutrition support team. The study design had incorporated the process of theoretical sampling to support the constant comparative approach. However, the local nutrition support team only had twenty five patients receiving HPN under their care. The study inclusion criteria were such that a small number of patients did not meet the inclusion criteria; and of those who did meet the inclusion criteria, a few of them had declined to take part. The small number of patients who had given written consent to take part in this study, and were available for theoretical sampling could be considered to be a limitation of this study (Silverman, 2011).

In qualitative research the findings of the study pertain only to the limited setting in which they are obtained (Greenhalgh and Taylor, 1997). In this grounded theory study the techniques of purposeful and theoretical sampling were used to support the generation of theory, which explained the experiences of a small group of patients receiving HPN. The theory of 'living with loss' generated from this study might not be used to generalise the experiences of all patients receiving HPN. However, the study findings could provide relevance and resonance in the clinical practice of nutrition support teams who looked after patients receiving HPN.

3.14 Chapter summary

The literature review described in chapter 2 highlighted a paucity of information on the experiences of patients receiving HPN in the UK. Qualitative methods was chosen for this study in order to answer the research question using interview data provided by patients receiving HPN. A grounded theory study goes beyond description in order to generate or discover a theory, a unified theoretical explanation (Corbin and Strauss, 2008). This study collected interview data and analysed the transcript jointly,

together with the use of purposeful and theoretical sampling in order to demonstrate the principles of the grounded theory methodology.

This chapter explained in details the methodology used for sampling, data collection, preparation of transcriptions verbatim, the strategies of analysis, the analytic tools and the analytic plan which explains the processes followed in developing concepts, categories and the emerging theory from the data collected.

Chapter 4 DATA ANALYSIS

4.1 Introduction to chapter

The first part of this chapter described the analysis of data in the form of interview transcripts, demonstrating the analytic processes which were described in chapter 3. Detailed descriptions are included in order to demonstrate the stages of initial coding and other coding techniques. In-vivo codes from the study participants were used extensively to support the generation of categories using a range of techniques developed by scholarly grounded theorists. The second part of this chapter explained the processes of defining a category, subcategories, looking for connections between categories and subcategories.

4.2 Demographic details of participants

The study information pack was sent to patients who attended HPN outpatient clinics between October 2012 and July 2013. A total of 15 patients gave written consent but only twelve of them agreed to be interviewed by the researcher. Information on participants' characteristics is summarised in Appendix 15. Collection of demographic and contextual information was not specified as part of the ethical submission, because confidentiality would be compromised, given the low number of patients in this specialist clinical area in the locality. Therefore, it would be inappropriate to include any more than the basic information on chronic ill health and sudden illness (see Appendix 15).

4.3 Generation of open codes

In the classic grounded theory Glaser and Strauss emphasized *'the coding of incidents for a category, as well as comparing it with the previous incidents in the same and different groups coded in the same category'* (Glaser and

Strauss, 1967 p.106). During first reading of the transcript, I noted that P#1 described her experiences with sudden illness, followed by the development of life-threatening complications affecting her bowels and the need for emergency surgery. It was rich in description on living with stoma and HPN. Her daily life was preoccupied with the need to manage stoma and HPN, and they became inseparable in terms of their impact on and interactions with the individual's health and life-style. Therefore, it was considered necessary to take into account both the stoma and HPN when analysing interview transcripts in order to achieve the aim of this study.

A short phrase or code was used to define a segment of interview transcript giving meanings to what the segment was about (Charmaz, 2006). Codes conceptualise the words of participants and incidents described by them (Strauss and Corbin, 1998 p.58). This is illustrated by some examples of initial open codes generated from transcript P#1 in Table 3:

Table 3 Examples of initial open codes

Transcript excerpts	**Initial open codes**
'they had to do a stoma to get rid of blood clot'.	*'trauma, staying alive from serious complications, lack of choice'.*
'the outcome of the stoma was such a great amount and I weren't keeping any fluids'.	*'failure to cope with stoma losses'.*
'I have to carry it all night. If I go to the kitchen, I have to carry it; I want to go upstairs I got to carry it upstairs. I'm just tired of it'.	*'restrictions with mobility around the house with HPN equipment'.*

This process of coding each line or several lines of the transcript allowed me to *'break into the data'* (Corbin and Strauss, 2008 p.59) by condensing the text in order to develop an impression and understanding of the information provided by the participant. These open codes generated were analysed in order to make interpretations from the participant's descriptive account. Charmaz described initial coding as a way to *'distil and sort them into segments which can be used for comparison with other segments'* (Charmaz, 2006 p.3). This advice on coding transcripts was followed.

4.3.1 Labelling of small data segments (word-by-word)

This involved the labelling of a data segment with a code in order to reflect the participant's *'meaning, action and reaction' (Charmaz, 2006)*. The purpose of this initial word-by-word-coding was to look for processes, actions and interactions described by the participant. There were many open codes generated around the stoma and HPN from transcript P#1. When I came across significant or interesting remarks made by this participant, I labelled these as in-vivo codes. These were exact words or phrases used by the individual and these codes captured and reflected her views and experiences with the stoma and HPN (Glaser and Strauss, 1967). It was important to focus on the participant's perspectives (Glaser, 1978), as well as keeping an open mind exploring the *'theoretical possibilities'* (Charmaz, 2006 p.47) rather than just the participant's narratives.

4.3.2 Labelling of in-vivo codes

Charmaz described the use of in-vivo codes as *'symbolic markers of participants' speech and meanings'* (Charmaz, 2006 p.55). I used these in-vivo codes to highlight transcript segments for interpretation, comparison and analysis in support of the phenomena that the data was describing (Charmaz, 2006). Each in-vivo code is labelled and given a dimension of

either ‘positive’ or ‘negative’ experience. These in-vivo codes were analysed and compared with those from other participants at a later stage in the generation of categories. Examples of in-vivo codes are shown in Table 4. As I continued to collect data, code and analyse subsequent transcripts, in-vivo codes on the stoma and HPN were noted from each transcript.

Table 4 Examples of in-vivo codes from transcript P#1

In-vivo codes on stoma	**Open codes**
‘I find it quite binding’	Frequent stoma changes (negative experience, frustration with stoma care (negative experience)
‘I’m so restricted ……. plan around stoma’	Restrictions from stoma care (negative experience), lack of choice (negative experience)
‘if I get rid of stoma, I might get rid of the problem’	Health problems caused by stoma (negative experience), lack of choice (negative experience)
In-vivo codes on HPN	**Open codes**
‘I have to carry it all night. If I go to the kitchen, I have to carry it; I want to go upstairs I got to carry it upstairs’	Restrictions from HPN routine (negative experience), lack of choice (negative experience)
‘I don’t like it. I really don’t like. I have to have it’	Feeling forced to have HPN (negative experience), lack of choice (negative experience)

Additional exploratory questions were not asked when I interviewed the participant. I used these to look for processes during open coding in search of possible relationships between stoma and HPN. These questions are shown in Table 5 below. I used these same questions when writing theoretical memos to evaluate and make decisions on the selection of the large numbers of codes during axial coding and selective coding to support the emerging categories and core theories.

Table 5 Additional exploratory questions used for open coding
What process is at issue here? Under which conditions does this process develop? How do(es) the research participant(s) think, feel, and act while involved in this process? When, why, and how does the process change? What are the consequences of the process? (Charmaz, 2006 p.81)

4.3.3 Labelling of large data segments (line-by-line, incident-by-incident / event)

Transcript P#1 was rich in incidents and events reflecting how, when, where and with what consequences when living with the stoma and managing HPN. By labelling large data segments, the open codes generated provide contexts for the participant's views and experiences in physical health, practical, social and emotional consequences of living with the stoma and HPN. This coding technique is also used to interpret and refine initial open codes and groups of open codes, in search of similarities and differences. By returning to the data segments where these in-vivo codes were located, I gained fresh insights and saw nuances in the data (Charmaz, 2006). Examples of open codes on stoma and HPN generated from transcript P#1 are shown Table 6 below.

An overview of the large number of initial open codes highlighted the impact and influences of the stoma and HPN on the participant's life both at home and in social situations. These open codes generated from transcript P#1 supported the notion of the two themes: stoma and HPN. These two themes were taken into consideration and I used them as guides during open coding of transcripts P#2. I used the same analytic prompts, processes and exploratory questions to label in-vivo codes on stoma and HPN from transcript P#2. Examples of in-vivo codes on stoma and HPN from

transcript P#2 are shown in Table 7. These in-vivo codes provided a strong impression on the significance of the stoma and HPN in the participant's life. They showed similarities to those generated from the previous transcript P#1. These clues identified from transcript P#1 and P#2 were followed up when coding subsequent transcripts.

Table 6 Examples of open codes from transcript P#1	
Open codes on stoma	**Dimension**
'failure to cope and frustration with high stoma losses'	negative experience
'feeling unwell, dehydrated, tired and weak'	negative experience
'loss of independence with everyday life'	negative experience
'restrictions in choices of foods and drinks, clothes'	negative experience
'loss of self-image from having stoma bag'	negative experience
'shock to see undigested foods in stoma bag'	negative experience
'lack of control over stoma losses and frequency'	negative experience
'anxiety with stoma bag leaking or falling off'	negative experience
'anxiety when using public toilets'	negative experience
'resourceful in avoiding stoma leaks'	positive experience
'resourceful with car journeys'	positive experience
'resourceful with toilet facilities in social settings'	positive experience
Open codes on HPN	**Dimension**
'realisation with need for HPN'	negative experience
'can't live without due to problems with dehydration'	negative experience
'being noticed for looking different from others'	negative experience
'feeling unattractive with stoma bag and HPN feed'	negative experience
'being dependent on others for support'	negative experience
'loss of job, freedom and independence'	negative experience
'restrictions and loss of mobility around the house'	negative experience

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Table 7 Examples of in-vivo codes from transcript P#2	
In-vivo codes on Stoma	**Open codes**
'I'm always thirsty and no energy… I just, I just felt ill….I couldn't put one foot in front of the other (laugh)… it was awful I just felt so ill, just had to lie down'	Lack of choice (negative experience), accepting chronic ill health (negative experience)
'I can't get over carrying a bag of shit around'	Not accepting stoma (negative experience), loss of self-image (negative experience)
'when I came out of hospital, I felt I've been had a baby and come home without it'	Grieving for loss of body image (negative experience)
'loss of part of your body…loss of part of your normal function I suppose'.	Grieving loss of body image (negative experience)
In-vivo codes on HPN	**Open codes**
'we've been on cruises which are so much better because you can take as much stuff as you want'	Taking holiday (positive experience), not restricted by stoma or HPN equipment (positive experience)
'I think I'm normal and I know I'm not'	Accepting loss of self-image (negative experience)
'we can go anywhere so it doesn't affect our social life'	Enjoying social life (positive experience)
' I am alive now and I think without it I wouldn't be here…definitely'	Improved health with HPN (positive experience), accepting HPN (positive experience)

4.3.4 Refining initial open codes

These in-vivo codes on stoma and HPN generated from transcripts P#2 provided further support to the two themes: stoma and HPN. These two collections of initial open codes from transcript P#1 and P#2 were reviewed for open codes which represent the similarities and differences between stoma and HPN. Similar initial open codes which described the effects of stoma, and of HPN on the participants were grouped together.

Examples of initial open codes on stoma and HPN replaced by final open codes are shown in Tables 8 and 9 below respectively. Generation of these final open codes on stoma and HPN illustrates the use of questioning and comparing data to describe a phenomenon which was being suggested by the initial open codes.

More than one final open code may be generated from the same piece of data segment reflecting the complexity of the phenomenon being described and shared by the participants. This process condensed the data segments further. These final open codes supported the following concepts about the stoma and HPN: physical health, practical, social and emotional impact.

Table 8 Examples of similar initial open codes on stoma replaced by final open codes from transcript P#1 & P#2	
Initial open codes: *'the outcome of the stoma was such a great amount and I weren't keeping any fluids' P#1* *'I can go to toilet and empty this bag twenty times a day' P#1* *'I need to go somewhere with a lot of toilets' P#1* *'..be careful where I go because I need toilets' P#1* *'I don't know what happened but my bag fell off' P#2*	**Initial open codes:** *'makes me tired, I can't walk upstairs…makes me feel poorly and weak' P#1* *'I 'm always thirsty and no energy' P#2* *'I have got an ileostomy that is my main problem with eating' P#2* *'Just no energy… I was losing a lot of fluids' P#2* *'Just no energy… I was losing a lot of fluids' P#2*
Final open codes: *'high volume of stoma losses', 'frequent access to toilets'*	**Final open code:** *'tiredness, weakness and lack of energy',* *'poor physical health',* *'dehydration from high stoma losses'*

Table 9 Example of similar initial open codes on HPN replaced by final open codes from transcript P#1 & P#2	
Initial open codes: *'I don't like being on long term for twelve hours in here every day' P#1* *'we've not been able to go away or holiday' P#1* *'I was very independent before' P#1* *'I don't like being restricted' P#1* *'you can't go out, or you'll have to go out and come back and have it put on at eight o'clock' P#1* *'I've not been on holiday for a long time' P#2* *'I wouldn't want to go to a hotel and take all my stuff with me' P#2* *'I wouldn't want to take my gear* there' *P#2*	**Initial open codes:** *'I'm feeling quite well and I look quite well…everybody says I look quite well' P#1* *'if I haven't been on it, I just feel dehydrated and I will end up in hospital, so I've got to have it' P#1* *'I mean I can put washing out, you know things like that, but I am careful' P#1* *'well, it puts my weight on, I felt I have got a lot of energy' P#2* *'I'm alive now and I think without it I wouldn't be here… definitely' P#2*
Final open codes: *'strict HPN routine'* *'restricted by 12 hours of HPN infusion time'* *'loss of independence'* *'lack of choice'*	**Final open codes:** *'improved physical wellbeing & appearance'* *'dependent on HPN'* *'lack of choice with HPN'*

From the collection of final open codes on stoma and HPN generated from transcript P#1 and P#2, they revealed some similarities in the participants' reactions, actions and interactions with the stoma and HPN. These open codes revealed the practicalities of living with these two health interventions at home. They supported the notion of two early categories: living with stoma

and living with HPN in support of the two phenomena: stoma and HPN which were first identified from the in-vivo codes discussed earlier. These two early categories were explored further in the next stage of open coding. This coding process outlined above continued throughout the study with each participant interviewed.

4.3.5 Generation of focused codes

The technique of focused coding, developed by Glaser, refines and generates new codes which are more directed, selective, and conceptual than word-by-word, line-by-line, and incident-by-incident (event) coding (Glaser, 1978). Charmaz describes the use of focused coding to *'sift through large amounts of data in search of early categories'* (Charmaz, 2006 p.57-58). This coding approach is appropriate in order to refine the open codes on stoma and HPN, and then to look for patterns of events, circumstances, actions, interactions and responses.

Appendix 11a and 11b illustrated the open codes on stoma and HPN generated from the interview transcripts respectively. The characteristics for stoma and for HPN were revealed using a range of open coding techniques such as word-by-word, in-vivo, line-by-line and incident-by-incident coding. These two sets of open codes on stoma and on HPN were refined using the technique of focused coding. This meant that similar codes were grouped together revealing a particular pattern and a sequence of events. These in turn illustrated the phenomena: stoma and HPN. The properties and dimensions on stoma and HPN, and the corresponding coping strategies were integrated and refined using the techniques of focused and axial coding (see Figure 1 Outline of analytic processes, Section 3.7.9 Analytic processes). Examples of focused codes on stoma and HPN are shown in Table 10.

These focused codes described in detail the features of stoma care and HPN management respectively. The data also reflected the wide range of responses provided by the participants. These new data gave a fresh and renewed perspective on the two early categories. Following interpretation of these focused codes, the realities and practicalities of living with the stoma and HPN became evident. This information supported the need to change the two early categories to: living with stoma and living with HPN. Appendix 11 details a theoretical memo that explains the thought processes involved in the formation of these two early categories: living with stoma and living with HPN.

Table 10 Examples of focused codes on stoma and HPN from transcript P#1 & P#2

Open codes on stoma	**Focused codes on stoma**
'failure to cope and frustration with high stoma losses'	*'high volume of stoma losses', 'lack of control (stoma volume & frequency)'*
'feeling unwell, dehydrated, tired and weak'	*'poor health, tiredness'*
'anxiety with stoma bag leaking or falling off'	*'anxiety from stoma leaks'*
'limitations in choice of foods and drinks,	*'lack of choice (food & drink)'*
'desire to disguise stoma bag'	*'loss of self-image'*
Open codes on HPN	**Focused codes on HPN**
'realisation with need for HPN'	*'dependent on HPN'*
'can't live without due to problems with dehydration'	*'improved physical wellbeing & appearance'*
'being dependent on others for support'	*'reliant on help from others'*

4.3.6 Refining categories

Having identified the two phenomena: stoma and HPN, the two early categories: living with stoma and living with HPN were conceived, and the third interview was carried out in order to explore the phenomena. Transcript P#3 was coded and analysed with the same coding techniques described in sections 4.3 to 4.3.3. These open codes from transcript P#3 were compared with the focused codes generated in the previous section. The names for these focused codes were reviewed and changed as new data were provided.

The process of data collection, open coding and comparison of focused codes using constant comparative analysis was carried out simultaneously with subsequent interviews. I continued to attend HPN out-patient clinics and obtain written consent from patients who agreed to be interviewed at home. Having interviewed the next participant, I prepared the transcript within the same week and this was followed by open coding using the techniques described earlier. Focused codes generated from each transcript were compared for similarities and differences, and then organised into these two early categories or causal conditions: living with stoma and living with HPN.

For the causal conditions living with stoma and living with HPN, these focused codes were interpreted further in terms of their relationships, significance and corresponding consequences to the participants (Charmaz, 2006). This process of selection, interpretation and organisation into sub-groups of focused codes revealed relationships as well as patterns between these codes. The data provided insights into the participants' lives once they were discharged from hospital. These relationships and patterns, developed

from focused codes, supported two subcategories: stoma care and HPN treatment (Strauss and Corbin, 1998 p.101).

This analytic process was used to check my interpretations against preconceptions about stoma and HPN which I have become familiar with during the course of clinical practice in hospital. The theoretical memo was updated to record these thought processes and decisions were made in refining the categories. Figures 2 and 3 illustrate the relationships within focused codes on stoma and HPN respectively. These two new subcategories: stoma care and HPN treatment are discussed next.

4.3.7 Defining a category

Glaser and Strauss defined a category as a *'conceptual element in a theory'* (Glaser and Strauss, 1967 p.36). This definition was refined by Strauss and Corbin who described a category as *'a concept that stands for a phenomenon, with its characteristics defined in terms of its properties and dimensions'* (Strauss and Corbin, 1998 p.101).

4.3.8 Describing properties of the categories and subcategories

The open codes generated from initial coding represented the participants' descriptions of their responses, actions and interactions (Charmaz, 2006 p.91) to the two phenomena: stoma and HPN. During focused coding the characteristics of stoma and HPN were explored and developed extensively. These focused codes were reviewed and interpreted further, and some of these were raised as two early categories: stoma characteristics and HPN characteristics. These early categories were explored further in order to reveal their contribution and significance to the core category.

These focused codes represented the impact and effects of stoma and HPN on the participants' health and life-style. Similar focused codes were organised into a group which represented a pattern or a specific aspect of stoma care and HPN routine, and the participants' responses to these. The following groups were identified from this process: stoma output, frequent access to toilets, dietary changes, health changes, activities at home and in social situations.

During constant comparative analysis the original focused codes generated from each interview transcript were reviewed and compared with those which were identified from earlier analysis. The original focused code for *'undigested foods in stoma'* was renamed and replaced by the final focused code *'dehydration and malabsorption'.* This final focused code described more accurately the consequence of stoma losses on the physical health of the study participants. Examples of original focused codes developed into final focused codes on stoma and HPN are shown in Tables 11 and 12 respectively.

Figure 2 Relationships within focused codes on stoma

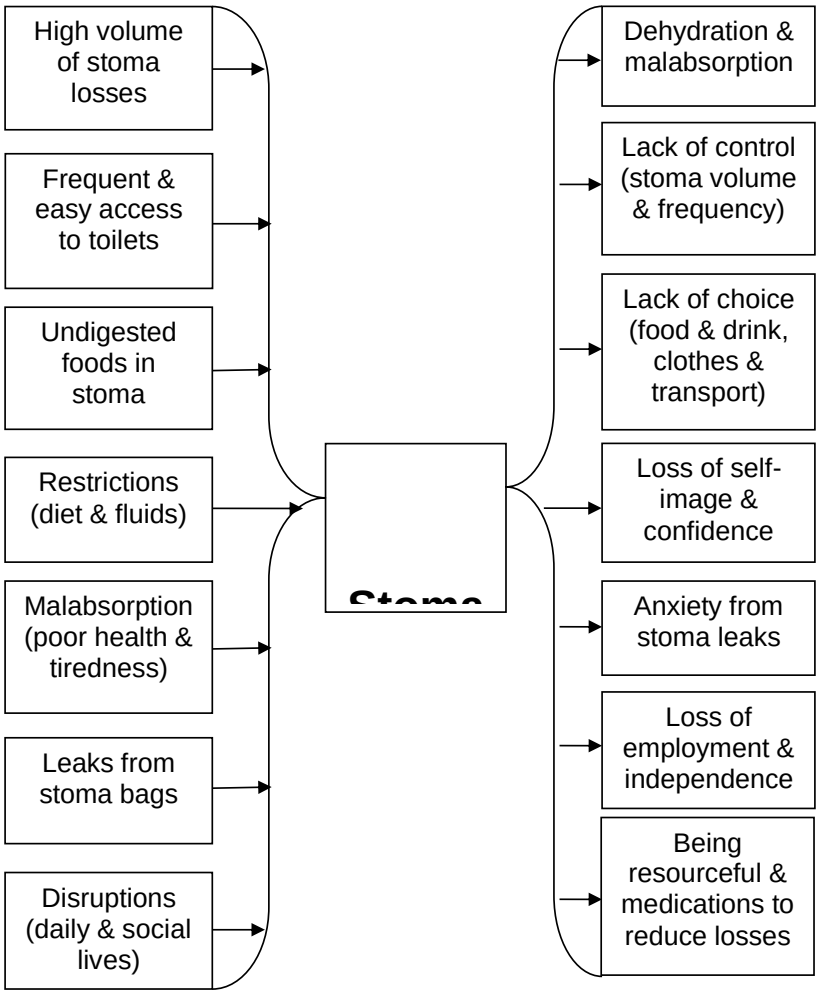

Figure 3 Relationships within focused codes on HPN

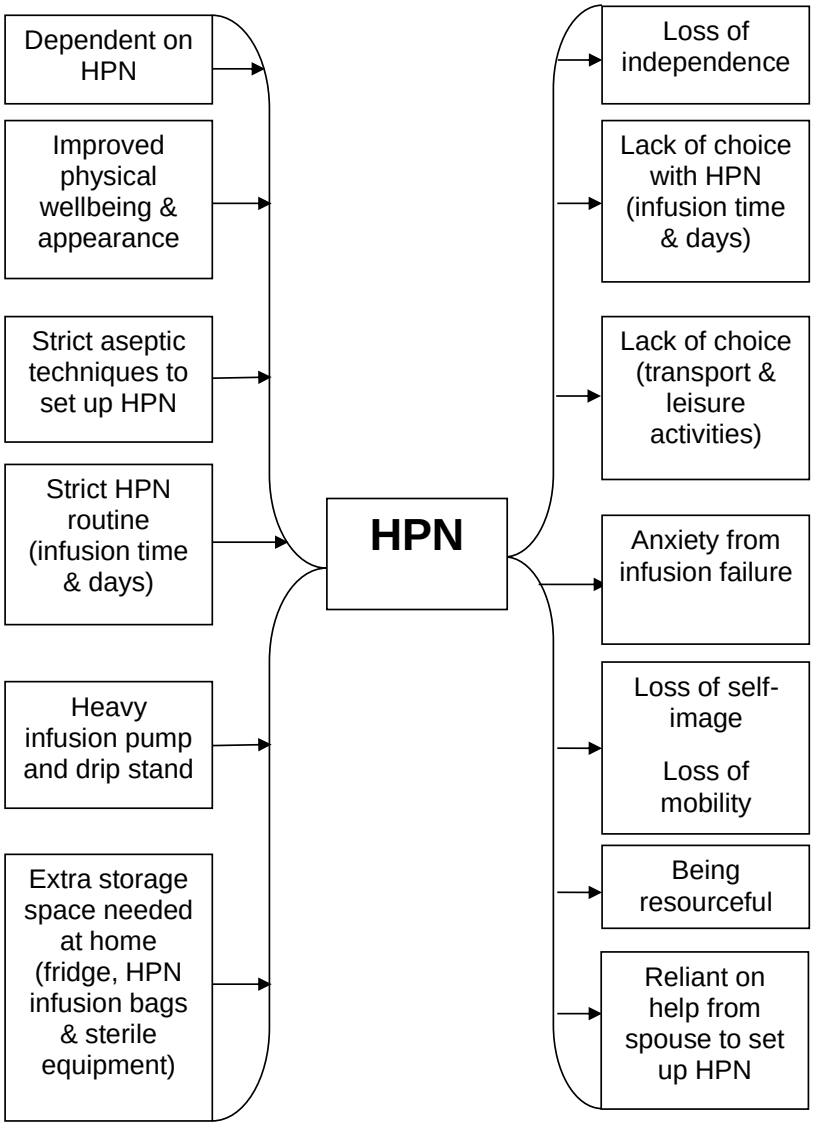

Table 11 Original focused codes developed into final focused code on stoma	
Original focused codes on stoma: *'malabsorption of foods and fluids'* *'undigested foods in stoma bag'* *'undigested foods in stoma'* *'tired and poor health'* *'I was losing a lot of fluids'*	**Final focused codes on stoma:** *'dehydration and malabsorption'*
'restricted to dark coloured clothes' *'limited choice of clothes'*	*'lack of choice'*
'worried about stoma leaks' *'helplessness when stoma leaked'*	*'anxiety from stoma leaks'*

Table 12 Original focused codes developed into final focused codes on HPN	
Original focused codes on HPN: *'clothing to disguise HPN bag & infusion pump'* *'have control over travel plan for holidays'*	**Final focused codes on HPN:** *'being resourceful'*
'being noticed for looking different' *'desire to look normal'*	*'loss of self-image'*

4.3.9 Refining categories

Charmaz's guidance on raising a code to a category was followed to refine the large number of focused codes in each category (Charmaz, 2006 p.92).

A group of similar final focused codes were interpreted and then raised into a sub-category, which has a different name to the focused codes. The pattern of similar focused codes provides clues on a range of issues associated with physical health, stoma care, HPN routine, social interactions and emotional responses which were common (or unusual) amongst the study participants. These two early categories were represented by stoma and HPN, as they provided a much closer fit to the data provided by the participants. These two categories were used to set the analytic direction when exploring the patterns of focused codes for similarities and differences within and between datasets.

4.3.10 Defining subcategories

The process of data collection, open coding and constant comparison analysis was maintained, whereby the recorded interview was transcribed verbatim and then coded using the same range of coding techniques described earlier. These codes were compared for similarities and differences with those generated from other transcripts, which in turn supported the generation of a total of six subcategories. Appendix 11a Theoretical memo 3 on open codes on stoma and Appendix 11b Theoretical memo 4 on open codes on HPN, illustrated the ranges of focused codes which supported the categories stoma and HPN (see Table 13 Subcategories for stoma and HPN). These focused codes were sorted and refined using the technique of axial coding, which in turn revealed the properties and dimensions of the subcategories for stoma and HPN (see Tables 14 and 15 for Properties and dimensions of subcategories for stoma and HPN respectively).

These two categories: stoma and HPN were refined with the use of the paradigm model (see Table 16: A paradigm model for the category stoma and Table 17: A paradigm model for the category HPN). This analytic

process revealed the consequences of not maintaining stoma and HPN. These in turn supported the sense of loss imposed upon these participants in a range of personal, home and social situations. Table 13 illustrates the subcategories for the two categories stoma and HPN.

Table 13 Subcategories for stoma and HPN

Subcategories for stoma	**Subcategories for HPN**
Maintaining stoma output	Maintaining HPN infusion routine
Access to toilets	Access to technical help to set up HPN infusion
Managing dietary changes	Mobility with HPN equipment
General health changes	General health changes
Managing activities and social interactions	Managing activities and social interactions
Living with loss	Living with loss

Each subcategory has a range of properties and their dimensions were generated to represent the specific condition(s), consequences and relationship(s) to each of the two phenomena: stoma and HPN. These properties and dimensions were refined as more information was collected during simultaneous data collection and coding. This approach was used to generate the subcategory maintaining stoma output, which was raised from the focused code high volume of stoma losses. This subcategory represented the practical aspects of stoma care that participants had to learn, and the consequences of their interactions:

Watery consistency of stoma output.

Compliance with diet & medication to reduce stoma volume and frequency.

Frequency of leaks / accidents from stoma.

Tables 14 and 15 provide a summary of the properties and dimensions of the subcategories for the two categories stoma care and HPN treatment respectively.

As each subcategory was refined with new focused codes generated from subsequent transcripts, I achieved a deeper level of awareness and understanding of the stoma and HPN from the participants' perspectives. I also gained theoretical sensitivity on how participants live with and manage the stoma and HPN following discharge from hospital. Their narratives are central to this exploratory study. The theoretical memo was updated to record the thought processes involved when reviewing a data segment for possible property and its dimension, and the generation of subcategories for stoma (Appendix 12 Theoretical memo stoma characteristics) and HPN (Appendix 13 Theoretical memo living with HPN) respectively.

Table 14 Properties and dimensions of subcategories for stoma		
Subcategories	**Properties**	**Dimensions**
Maintaining stoma output	Watery consistency	More --- Less
	Compliance with medication to reduce stoma volume & frequency	Full --- Variable
	Frequency of leaks / accidents from stoma	Few --- Often
Access to toilets	At home	Easy --- Difficult
	When going out	Easy --- Difficult
Managing dietary changes	Choice of foods and drinks	Broad --- Limited
	Disruptions at meal times	Never --- Often
General health changes	Energy /strength	Normal --- Low
	Thirst / tiredness	Never --- Often
	Body weight	Normal --- Low
	Dependence on others	Full --- None
Maintaining daily activities & social interactions	Independence	Normal --- Low
	Choice of clothes	Full --- Few
	Use of public transport	Often --- Never
	Social life / socialising	Full / Often --- None / Never
	Holidays & leisure activities	Often --- Never
	Employment	Maintained --- Lost
Living with loss	Anxiety	Often --- Never
	Depressed / depression	Often --- Never
	Embarrassed / embarrassment	Often --- Never
	Frustration	Often --- Never
	Desire to disguise	Often --- Never
	Normality	Maintained --- Lost
	Loss of self-image	Often --- Never
	Increased self-consciousness	Often --- Never
	Unfulfilled own desires / wishes	Often --- Never

Table 15 Properties and dimensions of subcategories for HPN		
Subcategories	**Properties**	**Dimensions**
Maintaining HPN infusion routine	Hand dexterity & eye sight	Good --- Poor
	Aseptic techniques	Good --- Poor
	Compliance with routine	Full --- Variable
Access to technical help to set up HPN infusion	From home care company	Regular --- Never
	From spouse or family members	Regular --- Never
Mobility with HPN equipment	At home	Easy --- Difficult
	Going out	Easy --- Difficult
General health changes	Energy /strength	Normal --- Low
	Tiredness	Never --- Often
	Body weight	Normal --- Low
	Dependence on others	Full --- None
Maintaining daily activities & social interactions	Independence	Normal --- Low
	Choice of clothes	Full --- Few
	Use of public transport	Often --- Never
	Daily activities	Full --- Few
	Social life / socialising	Full / Often --- None / Few
	Holidays (away from home / overseas)	Often --- None
	Choice of leisure activities	Full --- Few
	Employment	Maintained --- Lost
Living with loss	Anxious / anxiety	Often --- Never
	Depressed / depression	Often --- Never
	Embarrassed / embarrassment	Often --- Never
	Frustrated / frustration	Often --- Never
	Desire to disguise	Often --- Never
	Normality	Maintained - Lost
	Loss of self-image	Often --- Never
	Increased self-consciousness	Often --- Never
	Unfulfilled own desires	Often --- Never

4.3.11 Looking for connections between categories and subcategories for stoma and HPN

Strauss and Corbin developed the technique of axial coding to make connections between categories and their subcategories in order to provide *'precise and complete explanations'* about the phenomena, once some categories have been identified during earlier stages of analysis (Strauss and Corbin, 1998 p.124). This guidance was changed in their later publication and they advised that *'open coding and axial coding should go hand in hand'* (Corbin and Strauss, 2008 p.198). Their latter advice was followed in this study whereby once a possible connection was noticed between similar subcategories, this relationship was explored in future interviews to reveal the nature of the relationship.

Strauss and Corbin described a systematic approach or paradigm to axial coding which consists of three components (Strauss and Corbin, 1998 p.127-128):

The *conditions*	(circumstances and situations) when the phenomenon (a problem, an issue, an event or a happening) occurs;
The *strategies*	(actions and interactions) used in response to the phenomena;
The *consequences*	of strategies used.

This approach or paradigm model was used to explore each of the six subcategories generated from data on stoma and on HPN separately. Tables 16 and 17 provide a detailed explanation on the use of the paradigm model for the category stoma and category HPN with their corresponding subcategory maintaining stoma output, and maintaining HPN infusion routine respectively.

Table 16 A paradigm model for the category stoma

Conditions

- large volume watery losses from stoma.
- unpredictable losses from stoma.
- undigested foods in stoma bag.
- leaks and accidents from stoma bag.
- patient feels thirsty constantly.
- patient loses weight & feels weak.
- patient needs help with daily activities at home.
- patient needs frequent and easy access to toilets.

Strategies to maintain stoma

- patient avoids certain foods and drinks.
- patient takes medications to reduce losses.
- patient chooses places with plenty toilets.
- patient chooses dark clothes to disguise leaks & accidents from stoma.
- patient avoids unfamiliar places or travelling on long journeys.

Consequences of the actions & interactions made by the participant

Maintaining stoma care:

- patient has fewer stoma leaks or accidents.
- patient feels less thirsty & has more energy.
- patient knows where toilets are in familiar places.

Accepting stoma:

- patient maintains activities at home.
- patient maintains self-image.
- patient enjoys socialising & resourceful with travel plans.
- patient takes holidays.

Not maintaining stoma care:

- patient feels embarrassed with frequent stoma leaks or accidents.
- patient feels thirsty & tired.
- patient feels self-conscious with use of public toilets.

Not accepting stoma:

- patient needs help at home.
- patient feels depressed & regrets loss of self-image.
- patient avoids socialising or travelling on long journeys.
- patient takes no holiday & becomes house-bound.

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Table 17 A paradigm model for the category HPN

Conditions

- poor hand dexterity to connect infusion set to HPN feed bag.
- impaired eye sight to set up HPN infusion pump.
- poor aseptic technique to maintain ~~Hickmann~~Hackman line care.
- connects to HPN infusion between 12 to 14 hours a day, for three to seven nights a week.
- limited mobility at home due to weight of HPN infusion equipment.
- bulky HPN bag and infusion pump to carry when going out.
- needs equipment for HPN infusion (bags, infusion pump and drip stand) when on holiday.

Strategies to maintain HPN

- patient receives technical help from nurses / spouse / partner /family member to connect and set up HPN feeds.
- patient receives help from spouse / partner or family members for daily activities at home.
- patient stays at home for 12 to 14 hrs for HPN infusion time.
- patient avoids socialising to comply with HPN infusion routine.
- patient has limited choices for holidays and leisure activities.

Consequences of the actions & interactions made by the participant

Maintaining HPN infusion routine:	**Not maintaining HPN infusion routine:**
- patient feels well with improved physical health. - patient looks better & takes part in daily activities at home. - patient takes holidays. - patient maintains normality, enjoys socialising and leisure activities.	- patient feels tired & loses weight. - patient has poor general physical health. - patient stays at home. - patient loses normality, avoids socialising and stops leisure activities.
Accepting HPN routine:	**Not accepting HPN routine:**
- patient enjoys independence. - patients maintains self-image - patient feels no anxiety to disguise HPN from others. - patient considers possibility of part-time employment. - patient feels no frustration from being dependent on HPN.	- patient loses independence. - patient feels upset with loss of self-image. - patient feels anxious to disguise HPN from others. - patient feels depressed from loss of employment. - patient feels frustrated from being dependent on HPN.

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Open questions such as *'who, when, where, why, how and with what consequences'* (Strauss and Corbin, 1998 p.127) were used to explore and understand each subcategory and to identify the interactions and possible connections between them.

4.3.12 Understanding the connections between subcategories for stoma and HPN

Through the use of axial coding and the paradigm model, I gained a better understanding about each of the subcategories. This analytic process supported the identification of some possible connections between the six subcategories for each of the two phenomena stoma and HPN. Information presented in the paradigm model for each phenomenon illustrated the interplay between the subcategories whereby some could be causes or consequences of the phenomenon, and the associations between these were becoming evident. These connections were explored further in order to develop and understand the nature of the relationships and in order to generate core categories.

A paradigm model for the category stoma and HPN is shown in Tables 16 and 17 respectively. The model was used to organise and sort out the data so that possible connections between concepts derived from each subcategory were developed. These two groups of six subcategories conceptualised the study participants' views, experiences and emotions when coping with the stoma and HPN. The properties (and their dimensions) of each subcategory contextualised the reactions, actions, interactions and consequences of living with the stoma (see Table 14) and managing HPN (see Table 15) at home and in social situations.

4.3.13 Defining the connection between subcategories

The two subcategories maintaining daily activities & social interactions, and living with loss, demonstrated patterns of similarities in their properties for the two phenomena stoma and HPN. The rationale for these similarities was unclear at this stage. These possible connections between subcategories and categories were suggestive only. Therefore, it was appropriate to find out how these similarities came about, and to explore these connections between the two phenomena.

Purposeful sampling was used to recruit and to interview participants who had a stoma and were receiving HPN. The data collected were coded and analysed using the techniques described earlier. New data provided by study participants were compared with the condition causing these phenomena, strategies used to manage these phenomena, and the consequences of these phenomena. The six subcategories in each of the two paradigm models were updated during constant comparative analysis, whereby new data being provided by the next participant were coded and analysed using the range of coding techniques described earlier. This process was necessary to develop all the subcategories, their properties and dimensions before the next stage of selecting core category.

4.3.14 Integrating categories, subcategories and choosing core category

When using the grounded theory approach in qualitative research, the aim is to move beyond description and to generate or discover a theory that was derived from data (Strauss and Corbin, 1998). In focused coding the two categories stoma and HPN, and the subcategories for each phenomenon were generated along with their corresponding properties and dimensions. In axial coding using the Strauss and Corbin's paradigm model, the linkages between each category and its six subcategories were established.

The final analytic process involves the integration and refinement of the two categories, and the making of connections between categories and their subcategories (Strauss and Corbin, 1998, Charmaz, 2006). The technique of selective coding was used to choose and develop the core category, which describes the inter-relationship between categories and subcategories.

4.3.15 Choosing the core category

The core category is *'the main theme of the research'* (Corbin and Strauss, 2008 p.104), and it is *'the concept that all the other concepts will be related to'* (Corbin and Strauss, 2008 p.104). Strauss and Corbin advised that the core category may be evolved from the list of existing categories (Strauss and Corbin, 1998). The two subcategories maintaining daily activities and social interactions and living with loss appeared frequently in the data collected from the study participants for the two phenomena stoma and HPN. These two subcategories were considered to be possible core categories because they shared patterns of similarities in their properties, as well as their connections with the other subcategories.

However, there should be one core category in a grounded theory study (Glaser, 1978, Corbin and Strauss, 2008). The core category needs to bring other categories together in order to explain theoretically what the research is all about (Corbin and Strauss, 2008). Therefore, each of these two subcategories was evaluated further in order to choose the core category for this study. Corbin and Strauss have developed a list of criteria to use when choosing from two or more possible core categories. Table 18 gives details of the criteria proposed by Corbin and Strauss:

Table 18 Criteria for choosing core category
1. It must be abstract; that is, all other major categories can be related to it and placed under it. 2. It must appear frequently in the data. This means that within all, or almost all cases there are indicators pointing to that concept. 3. It must be logical and consistent with the data. There should be no forcing of data. 4. It should be sufficiently abstract so that it can be used to do research in other substantive areas, leading to the development of a more general theory. 5. It should grow in depth and explanatory power as each of the other categories is related to it through statements of relationship.' (Corbin and Strauss, 2008 p.105)

These criteria were considered in the selection of the core category. A theoretical memo with diagram was written to record the thought process used (see Appendix 14 Theoretical memo – Generation of concepts from two main categories: stoma and HPN).

4.3.16 Connections between the core category living with loss and the other categories and subcategories

The subcategory living with loss was chosen as the core category or central phenomenon after a review of all the theoretical memos using the above criteria. This category described the *'main theme of the research'* (Corbin and Strauss, 2008 p.104). It demonstrated a strong linkage with the two categories and between the twelve subcategories when the paradigm model was used to investigate the possible connections between these phenomena in previous section. These subcategories were saturated through theoretical

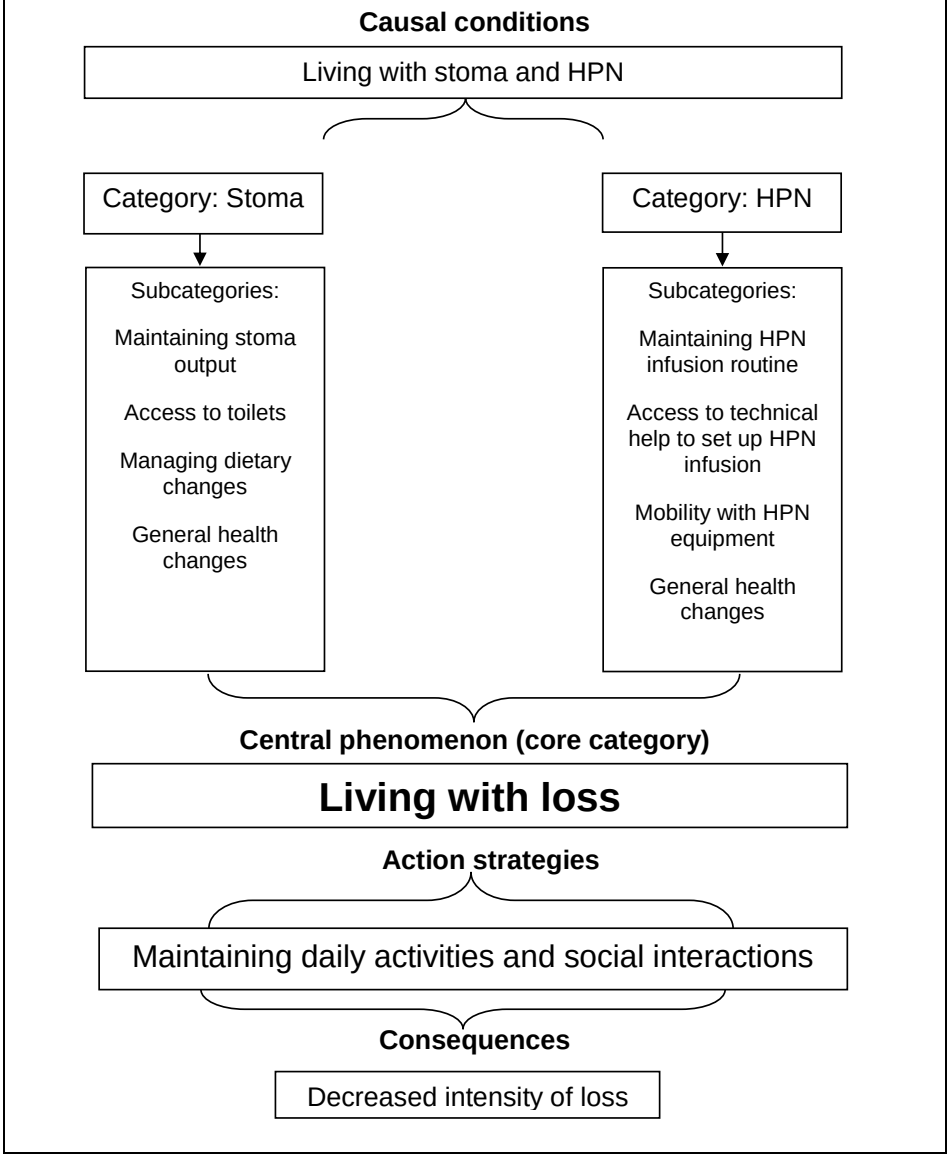
sampling. Figure 4 illustrates the connections between the two categories: stoma and HPN, and their corresponding subcategories.

Strauss and Corbin (1998) proposed that *'a phenomenon has the ability to explain what is going on'*, and it may be presented as *'a problem, issue, event or a happening which is significant to the individual'* (Strauss and Corbin, 1998 p.129). The authors explained that the actual conceptual names given to categories will not necessary point to whether a category describes a condition, an action / interaction or a consequence (Strauss and Corbin, 1998).

4.3.17 Display of process identified during data analysis to support the core category living with loss

Strauss and Corbin stated that *'bringing process into the analysis, is an essential part of our approach to theory building'* (Strauss and Corbin, 1998 p.163). In the previous section 4.3.11 on axial coding using the paradigm model, it demonstrated the use of *'asking questions'* and *'making comparisons'* to develop and link categories to subcategories systematically (Strauss and Corbin, 1998). Process is described as *'a series of evolving sequences of actions / interactions that occur over time and space, changing or sometimes remaining the same in response to the situation or context'* (Strauss and Corbin, 1998 p.165). This means data which represent the action / interaction may be strategic if they reflect the responses to problematic circumstances. Figure 4 illustrates the connections between the causal conditions, central phenomenon (core category) living with loss and the other categories and subcategories.

Figure 4 Connections between the causal conditions, central phenomenon (core category) living with loss and the other categories and subcategories



These principles were followed in this study when selecting and identifying data which explained the effect of changes in the causal conditions, has imposed on the central phenomenon living with loss, and on the action strategies used by the study participants to deal with loss. Also, when participants failed to or were unable to apply these strategies, the effects of these on living with loss were considered. These causal conditions and the participants' strategies and responses were discussed in a theoretical memo with the use of a detailed diagram to illustrate the complex interplay between the categories and subcategories (see Appendix 14).

Figures 5 and 6 provide a visual representation of the process ~~developed~~ developed during data analysis for stoma and HPN respectively. The~~se two~~ causal conditions of living with stoma and living with HPN have been presented separately in view of the complex interplays between the different elements. Although the initial causal conditions were different, these two health interventions were closely inter-related. The surgical procedure led to the formation of a stoma, and the study participants shared patterns of similarities and differences in their actions, interactions and emotions in maintaining stoma care.

Figure 5 Visual representation of the process developed during data analysis for stoma

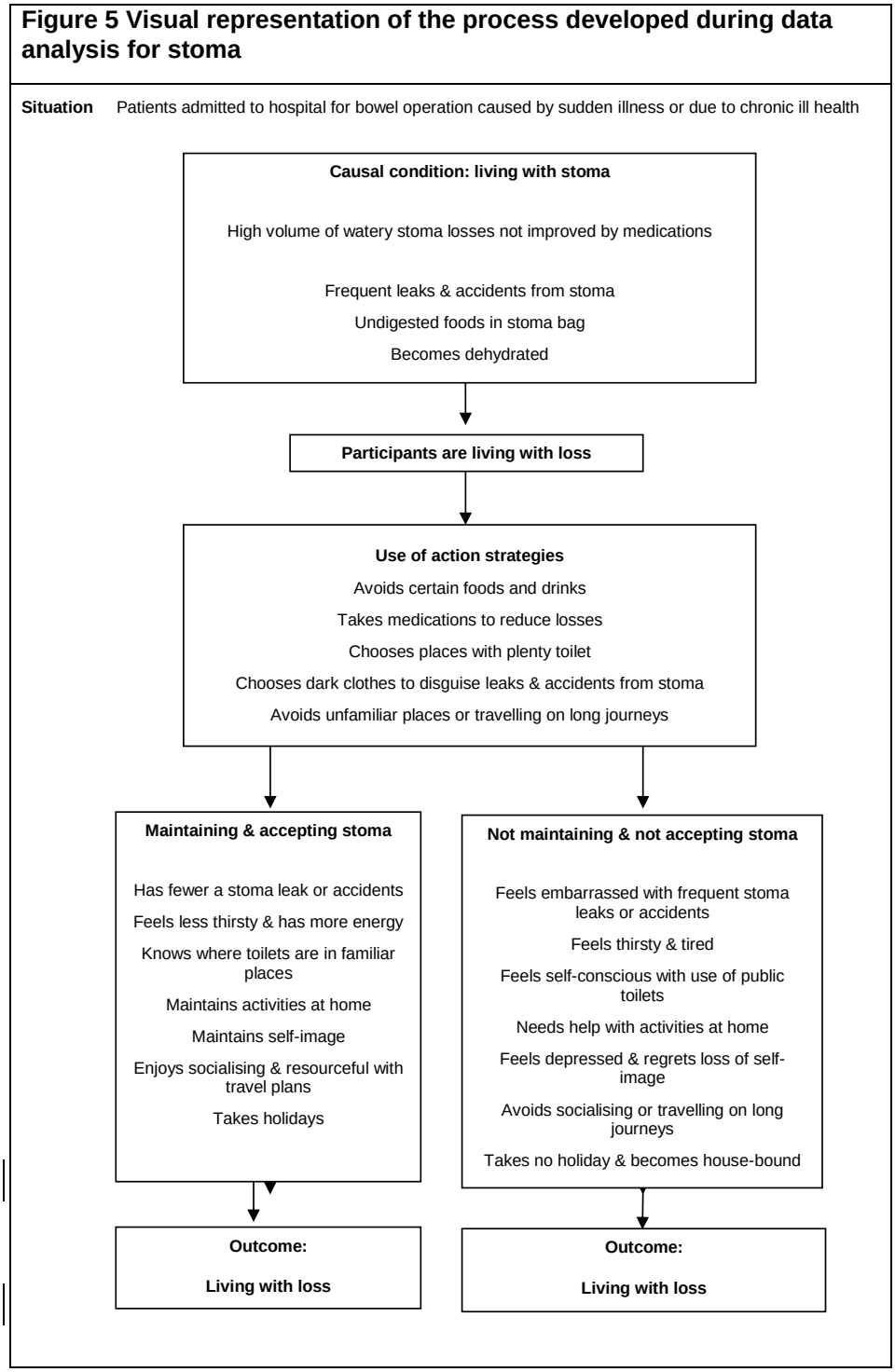
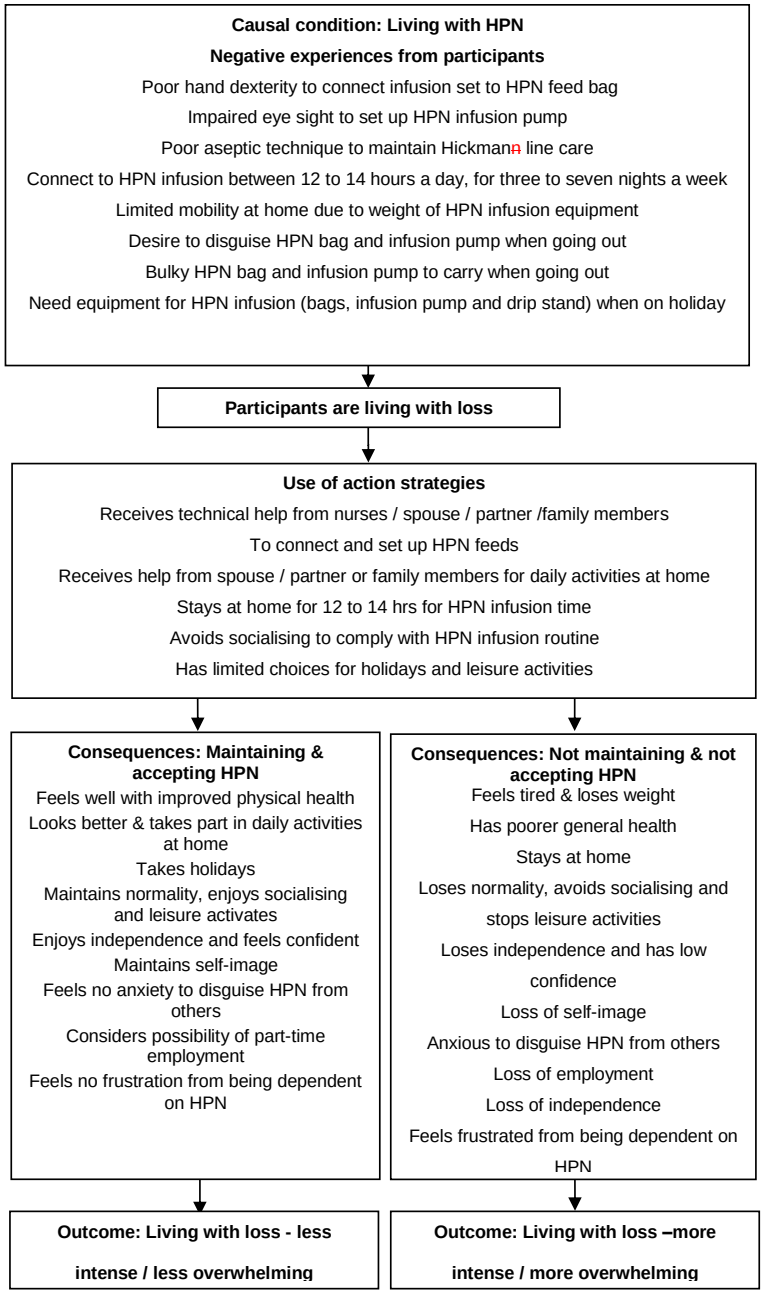


Figure 6 Visual representation of the process developed during data analysis for HPN

Situation Patients admitted to hospital for bowel operation caused by sudden illness or due to chronic ill health



4.3.18 Refining and defining the theory

Having identified the overarching core category living with loss in the previous section, the next stage involved the building of theory. Strauss and Corbin defined grounded theory as *'a set of well-developed concepts related through statements of relationships'* (Strauss and Corbin, 1998 p.15). During analysis of data provided by the study participants, their descriptions had been interpreted using a range of analytic processes. The concepts generated were interpreted abstractions constructed by the researcher.

From the list of interrelated concepts generated in support of the core category living with loss (see Figures 5 and 6), it represented a range of losses expressed and responded to by the participants. The loss varied in intensity and types. The conditions identified that could influence the central phenomenon of living with loss included participants who did not maintain both the stoma care and HPN treatment, due to the intensity of the restrictions and limitations imposed upon them.

The notion of living with loss signified the lack of choice imposed upon them by the stoma and HPN. This lack of choice provided a likely explanation for the sense of loss experienced by the participants in their daily lives and social interactions. This in turn represented the possible theory of living with loss, which is generated from data provided by the study participants and analysed using the grounded theory approach described by Glaser and Strauss (1967).

4.4 Chapter summary

This study followed the principles of simultaneous data collection and analysis. The analytic processes used illustrated the techniques developed by the leading grounded theorists: Glaser and Strauss (1967), Strauss and

Corbin (1998), Charmaz (2006) and Corbin and Strauss (2008). Each of these grounded theorists had an unique approach to open coding and methods of data analysis. Having considered these analytic approaches, I have chosen elements of coding and analytical techniques from the different grounded theorists. This decision was made on the basis that I found some techniques were easier to follow when coding the interview transcripts, and interpreting the codes using a combination of interpretative and constructivist approaches. There is general acceptance for qualitative researchers to choose and mix different coding and analytic techniques in grounded theory studies.

Open coding was used jointly with focused and axial coding, and two sets of six subcategories were generated from the data (see Tables 14 and 15). The integration of the categories, subcategories and the identification of the causal conditions for the core category living with loss, as well as the action strategies described by the participants supported the theory of living with loss experienced by all study participants. This theory is discussed in chapter 5.

Chapter 5 FINDINGS

5.1 Introduction to chapter

The previous chapter explained in details the analytic processes used to develop concepts, categories and the emerging theory. This chapter demonstrates the use of data, collected from the study participants using the methods described in chapter 3, to explain the relationships between the subcategories and the core category. These connections were used to explore the emerging theory which should be *'recognisable to participants'* (Strauss and Corbin, 1998 p.161). At each interview I used the issues raised by the previous participants to encourage the individual to describe what it was like having to maintain stoma care and HPN treatment at home and in social situations.

All the study participants underwent bowel surgery which led to the formation of a stoma. Purposeful sampling was used to recruit and to interview participants who had a stoma and were receiving HPN. Each participant underwent surgery for two possible clinical indications: sudden illness or chronic ill health. All study participants continued with stoma care and HPN treatment at home when they were discharged from hospital. The characteristics of the participants are summarised in Appendix 15.

Figure 4 in chapter 4 provided a visual representation of the connections between the causal conditions, central phenomenon (core category) living with loss and the two categories: stoma and HPN, and their corresponding subcategories:

Category:	**Stoma**
Subcategories:	maintaining stoma output, access to toilets, managing dietary changes, and

general health changes.

Category: **HPN**

Subcategories: maintaining HPN infusion routine,
access to technical help to set up HPN infusion,
mobility with HPN equipment, and
general health changes.

The following sections discuss the categories and subcategories, action strategies and consequences for the central phenomenon (core category) of living with loss, and how they integrated and supported the theory generated from the data. The discussion for stoma and for HPN is presented separately.

5.2 Category – stoma

All participants received stoma care training from clinical nurse specialists during their hospital stay. This included the techniques of applying and changing the stoma bag, as well as emptying the contents. Also they all received written dietary advice. Following discharge from hospital, all the participants took part in stoma care. They had to incorporate stoma care in their daily activities at home and in social situations.

Whilst at home each participant learnt about the stoma characteristics, ~~the stoma site~~ and in particular the high volume of watery stoma losses:

> *'The outcome of the stoma was such a great amount and I weren't keeping any fluids' P#1.*

> *'I didn't want to have baggy clothes, I wanted to wear normal clothes, I wanted to just be normal' P#2*

'The amount of time I went to the toilet, talking twenty plus times a day just to the toilet' P#5.

Participants were spending a lot of time to empty or change the bags frequently in order to minimise leaks and accidents. They also had to make changes with the fitting and the colour of clothes that they could wear in order to disguise the presence of the stoma bag underneath.

5.2.1 Subcategory – maintaining stoma output

The frequency to empty the stoma bag was also unpredictable and this had a significant impact on all the participants in maintaining stoma output:

'The stoma fills up quickly and you have to rush upstairs to go to the toilets' P#7.

'The bag holds about 300ml and when it gets full, it's heavy so it pulls away from the skin and then it leaks' P#8.

All the participants described how this lack of control with the stoma output, and its frequency, led to other practical issues in their daily life:

'You spent hours and hours upstairs [in the toilet] because you 'daren't come down or know you can't go out' P#6.

'At night it tends to go to water, and then you sleep and your bag fills up, and it's gone…you're swimming in this mess.' P#4.

5.2.2 Subcategory – access to toilets

While participants were settling back into their own environment, they had to continue with daily activities and take part in social gatherings. As a result of the high stoma output participants needed frequent and easy access to

toilets in order to empty the stoma bags. They had to choose carefully where they would go and take into account the accessibility of toilets:

> *'I have to use toilets four times on the way to Meadow Hall. It's a bind but it's the stoma that is a bind' P#1.*

> *'I can't go too far from a toilet because you get very little warning when you need to go.' P#10.*

With the unpredictability of high losses from stoma, participants described how they felt when they had leaks from stoma bags:

> *'You're trying to cover up the leak but people are watching you, a bit embarrassing really…' P#12.*

> *'I have been in a situation where it has leaked and you can just sense that trickling feeling and I have to leave everything and rush off to the toilet' P#7.*

5.2.3 Subcategory – managing dietary changes

Despite being dependent on HPN, all the participants could eat and drink. However, the loss of small bowel from the surgery had resulted in the loss of some of their ability to digest and to absorb food. The malabsorption of food was experienced by all the participants, and they are dependent of HPN in order to maintain health. They noticed the appearance of undigested foods in stoma:

> *'I can have tinned spaghetti on toast, and I can be eating that and I can go to the toilet and before I finish eating the spaghetti is down the toilet in stoma' P#1.*

'Basically everything I eat goes straight through anyway…I notice with cheese and fruits that …down the toilet straight away' P#5.

The appearance of watery contents in the stoma bag suggested that the participants had reduced ability to absorb enough fluid from drinks causing dehydration:

'If I have a drink it comes out straight into my stoma bag' P#8.

'If I have something to eat or drink, I can go to the toilet and empty this bag twenty times a day' P#1.

5.2.4 Subcategory – general health changes

All the participants experienced a range of general health changes caused by the malabsorption of foods and drinks associated with the high volume of watery stoma losses:

'I started feeling tired and me back hurt so I was getting a bit dehydrated' P#1.

'I was always thirsty and no energy…I just fell ill…I couldn't put one foot in front of another' P#2.

In order to keep the stoma output low, less watery and to reduce the frequency, the participants had to adhere to the restrictions on diet and fluids. This dietary advice was so different from the healthy, high fruit and fibre diets that they were familiar with before their surgery. This is how they described the lack of choice with foods and drinks:

'I wouldn't be able to eat vegs or fruits and only certain ones' P#3.

'A dietitian came to me and said…told me what I could eat, asking me, telling me I should be eating this, I should be eating that….and I used to say no, no, no…I don't eat something I don't like. If I don't like it I won't eat it and that's how it was'. P#12.

5.2.5 Action strategies for maintaining daily activities and social interactions

Prior to admission to hospital all the participants were living independently, either alone or with a spouse or partner. Four of the participants had a job during the time when they developed the sudden illness. Six of them were in retirement, but two participants were not in any employment due to their chronic ill health. During rehabilitation at home all the participants had to learn to integrate stoma care into their daily activities and in social situations.

During this period participants described a range of strategies and actions taken in order to balance the demands placed upon them from stoma care against the need to live at home alone, with spouse or partner, and to maintain a social life. In some cases participants were considering return to work.

The study participants came from a variety of social background and they experienced a range of general health changes during the early stage of recovering at home. Several of the participants received help from their spouse, partner or family members in order to maintain a range of daily activities at home:

'I got a lot of help from T [husband]. If I hadn't got him I wouldn't be here' P#2.

'My wife's cousin comes once a month to do a big clean for us' P#10.

'My niece or my brother…they do a hell of a lot for me and my big sister [sister-in-law]' P#5.

None of the study participants received help at home provided by primary health care organisations such as district nurses or social services.

During the early stages of rehabilitation at home, participants had to learn how to integrate stoma care into their daily activities. They described the impact of stoma care on daily activities in terms of restrictions with diet and fluids. The sense of loss in choosing what they would like to eat and drink normally versus what they were allowed was noted:

'Being a vegetarian for over thirty years, I can't bear the thought of eating meat and there is no way I can to back to eating meat' P#7.

'I can only have a cup of coffee perhaps at breakfast and little sips in between, and a drink at lunchtime but not with lunch' P#3.

One participant was dissatisfied with the dietary advice received from the Sheffield HPN team. She described how she used the Internet to search for additional information about dietary restrictions. This participant used her own initiatives to improve the range of food choices whilst maintaining the stoma output:

'I went on the internet … and I found a very similar booklet… the foods on there were low residue foods and were far more varied, the vegetables were far more varied including things like sweet potatoes, squash and bean shoots…it made such a difference to be able to have something else ….because if you are restricted to potatoes but they don't go with everything, and then swedes and parsnips are winter vegetable…what do you do now they are not in season?' P#7.

As the participants settled into their own environment, they had to take part in social activities. In terms of social interactions, participants described their sense of loss in choosing where they would like to go versus where they should or could go:

> *'I need to be safe, I need to feel I am in somewhere where there are plenty of toilets and I'm not going to queue and I'm not too far away from toilets' P#7.*
>
> *'I don't go anywhere; it's a real bug bear for me' P#5.*

This situation was influenced by the need to have frequent and easy access to toilet facilities so that they could empty the stoma bags in time, thus avoiding leaks and accidents. When they were going out all the participants took medications to reduce losses from stoma. They showed understanding in maintaining their medication regimen:

> *'I have to have them [Loperamide] in powder so I put them in water, I have six of them four times a day and two codeine four times a day' P#1.*

> *'I'm on Loperamide to thicken the output. When I take it [Loperamide] in some bitter lemon usually, just a tiny drop of bitter lemon and I don't notice the very bitter taste' P#3.*

All the participants would only visit places which offered easy access to toilets. Being able to choose where they could go was very important. When they were eating out in restaurants, they felt more at ease and reassured knowing that they could get to the toilets easily and to empty the stoma bag when needed:

> *'I like to sit near the toilets because while I am eating, I can go and empty [the stoma] and then I can come back' P#8.*

'We watch it [stoma] on the journey down to Cornwall and there are plenty places to stop and visit to the services and we can manage it [stoma] quite well, so we don't have a problem' P#9.

All the participants were resourceful in dealing with unexpected stoma leaks when they were in social situations. They developed their strategies to manage stoma leaks:

'You always got extra stoma stuff to carry with you, just in case you're are out and about and you do have a leak' P#8.

'I make sure that I have got either plenty of sticky stuff to hold it here or I took some supplies with me so that I could…if it did start to leak I could patch it up' P#12.

One participant made special arrangements when traveling by car in order to minimise the risk of a stoma leak:

'Sometimes if you are travelling you have to sit in front so you can stretch your legs so you are not cramped up because if you sit cramped, it comes off sometimes, the [stoma] bag' P#1.

When another participant was on a caravan holiday, she made special arrangements to avoid soiling of the mattress when the stoma leaked at night:

'I took rubber sheet thing and put it on the bed so if I did have an accident it's only the sheet that got it…but it's never happened when I was on holiday' P#4.

Some participants had to make changes to the choice of clothes to wear in order to disguise the stoma bag. This reflected the loss of choice adopted by the individuals in order to disguise stoma leaks:

> *'I have to wear dark cloths in case stoma goes. If I'm wearing something like pale blue and stoma goes it's just going to come through. I'm always concerned about the bag leak' P#1.*

But one participant regretted this loss of choice in the clothes that she had to wear instead of what she would like to wear:

> *'I didn't want baggy clothes, I wanted to wear normal clothes, I wanted to just be normal' P#2.*

This participant's comment implied a sense of loss in self-image resulted from the type of clothes that she had to wear in order to disguise the stoma bag.

Another participant described how he felt when the stoma bag leaked, and his description echoed the sense of loss in self-image in such a situation:

> *'You need a shower, clean clothes and I don't want this happening when I'm out. So I don't go anywhere. It's a real, real bug bear to me' P#5.*

5.2.6 Central phenomenon (core category) - living with loss and its connections with stoma

All participants had to integrate stoma care into their daily activities. They experienced a loss of self-image associated with the embarrassment caused by unpredictable stoma leaks and accidents:

'I find it [stoma leak] right degrading' P#1.

'You feel awful because you've made such a mess. I don't think anybody explained how you would feel and how it would be' P#3.

At night time the impact of a stoma leak was described as annoying by one individual who lived alone:

'you got to get up in the middle of the night, take your sheets off, get bed cleaned, and get everything and yourself cleaned, run a bath, get a clean nightie…all these…it's annoying, it shouldn't happened. This happened last night and half of my clothes are ruined, you got to throw them away, it's no good' P#4.

The extent of help and assistance needed by the participants varied considerably depending on their underlying health status. One participant was dependent on practical help from their spouse for stoma care because of the awkward position of the stoma:

'There is the one thing I cannot do which is to dress this [stoma] myself, my wife has to dress it for me. I couldn't bend down and see where to put things. I'll have to use a mirror which I have done but it's very, very difficult. If you get it wrong, you get the mess all over so it's much easier for my wife to do it´ P#9.

The very limited dietary choices of low residue foods were disliked by all the participants. These restrictions did not encourage compliance. One of them described how he had chosen to deviate from the dietary restrictions in on order to fulfil his own desires:

'I still eat fruit because I used to eat loads of fruits before the accident.

I still have it now and if I am feeling … sod the consequences, sod the toilets, I'll have some fruits and I'll have an orange, an apple or a pear … but it's only one every couple of days and I thought sod the consequences because I know it's going to make me go to the toilet but so is a curry…I'll have one may be once a fortnight, once a month and sod the consequences' P#5.

This participant expressed a strong dislike in the loss of choice in what he would like to eat, understanding that this would have a negative effect in maintaining stoma output.

During the early stage of rehabilitation at home participants had to take part in daily activities such as light house work and food shopping. Participants described their situations of living with loss in a range of daily activities:

'You can't continue with the activity that you were doing before' P#7.

'I just Hoover round and that's it, I'm drained, no energy' P#5.

Some participants had to refrain from some social interactions in case the stoma bag leaked. Participants were affected by this in different ways:

'I don't go out like I used to because if It happened [stoma leaked] when I'm out, what do I do? I'll be embarrassed sat in somewhere busy…I have to turn round and come straight back' P#5.

'I still feel like my quality of life has lessened dramatically … because whereas before there are no restrictions, there is no routine but now there is so much more anxiety around social situations' P#7.

'I don't do much visiting of people like friends simply because of all the stuff you have to take with you, all the stoma stuff. P#11.

After prolonged hospital stay all the participants had to learn to self-care at home. They noticed a loss of independence at home:

> *'Just little things like washing your hair, knowing that I couldn't bend over. I felt really tired from just washing my hair' P#7.*

> *'I fell…well like you do when you first come home, I didn't feel very happy at first and I had so much trouble showering and getting myself sorted' P#3.*

For a small number of participants they had to make decisions about employment prospects, and the need to change from a full to part time job in view of the changes in their general health. Three participants described how they felt when they learnt of the loss of job due to ill health:

> *'I used to work with people with learning difficulty…I'm not used to being a patient. I'm a carer, not a patient, I don't like it' P#1.*

> *'I begged and pleaded to the doctors to allow me to return to work. I went back to work and my boss looked at me once and he just said, 'You clothes off, work wear off, get dressed and get yourself home' P#5.*

> *'I have accepted the fact that working makes me worse so I know I'll never going to be able to hold down a full time job that is a fact' P#10.*

At the time of the study interviews, none of these participants who did have a job before they had the surgery were able to return to work following discharge from hospital. Participants described changes in their overall outlook to life and their wellbeing. They described an increased self-consciousness with the stoma and stoma leaks:

'I was thinking that everyone would know that I have actually got a stoma' P#7.

'It's demoralising, it's embarrassing…if it leaked when you're out' P#5.

In addition to this some participants also experienced a loss in confidence:

'I'm always concerned about bag leak…I find it right degrading' P#1.

'You feel that you don't want to go out; you just want to stay at home because you're alright at home' P#8.

Participants also described the extent of the loss in social interactions making them house-bound or they were becoming socially isolated:

'I hardly go anywhere because of my stoma' P#5.

'You know there is a wedding you can't go because you're too bad and that's what it did' P#6.

One participant disliked the use of public toilets and this is how she described her experience:

'I'm thinking is it going to flush toilet, do you know what I mean. And it's always things in your mind, 'I hope it's going to flush this toilet before I go out' P#1.

Another participant described how she felt about toilet when she was in unfamiliar places:

'I didn't know where the loos were at that point, so I was in a real flap. I was really anxious I thought this is just going to go everywhere' P#7.

One participant described the reactions from other disabled persons when she used the toilets designated for disabled users:

> *'I obviously don't look disabled and you get some really horrible people out there when I came out from the disable toilets…they looked down at me and I thought I'm disabled, I'm allowed to use these toilets. Because I'm not in a wheelchair or I'm not using a stick to walk with, I am not old so I should not use the disable toilet' P#8.*

With these constant worries about stoma leaks and accidents, participants held different views about taking holidays. A few participants had gone away but only for a weekend break:

> *I've been away a couple of times overnight but I've not been on holiday yet' P#8.*

One participant had reduced the amount of long distance driving associated with her hobby:

> *'I've not gone to as many dog shows and it is more to do with me not wanting to travel so far and something to do with the stoma' P#11.*

However, some participants had actively taken holidays and developed ways of making this work for their own situations:

> *'We've been on cruises which are so much better because you can take all, you can take as much stuff as you want' P#2.*

> *'We go off to Skegness and stay in a caravan which is as big as this house' P#4.*

'I'm going to Ireland which is going to be a twenty-four journey more or less. We should carry the stuff with us like we normally do. It's the same when we go down to Cornwall or anywhere else 'P#9.

'We've been to Benidorm and to Australia this year and that was the third time' P#10.

Each of these participants had a chronic ill health condition prior to the surgery which led to the formation of a stoma. They appeared more prepared and undeterred by the need to integrate the restrictions and limits imposed upon them by stoma care into their daily activities and social interactions, than did those participants who suffered sudden illness.

5.2.7 Summary on category - stoma

During their hospital stay all the participants learnt about stoma care from clinical nurse specialists. They were competent in changing the bag and emptying the contents before it leaked. Following discharge from hospital, each participant had to work out how to integrate stoma care into their lives so that they were able to maintain daily activities and social interactions. All participants had negative experiences from some aspects of stoma care, in particular the unpredictable stoma leaks and accidents. The main focus for each participant was to prevent and minimise the risk of stoma leaks or accidents as much as possible. In doing so they were living with loss imposed upon them by the need to maintain stoma care.

5.3 Category - HPN

The second causal condition to be discussed is that of HPN treatment. By the time the study participants were discharged from hospital, they were all reliant on HPN in order to maintain their nutritional and fluid requirements. Each participant had a different level of reliance on HPN depending on how

much of the small bowel was resected during surgery. Some participants needed HPN infusion every night but a few of them only needed HPN infusion on three to five nights a week. Several of these participants were having intravenous infusion on the nights when they were not having HPN feeds. The variations in infusion types and frequency were a reflection of the extent of their malabsorption status.

The composition of the HPN infusion was complex. Each HPN infusion was prescribed by the HPN team and the volume ranged between 2000 to 3000ml. Therefore, the infusion time ranged from at least twelve to fourteen hours in most cases. The hospital clinical nurse specialist provided extensive training and supervision to the participants to ensure that they understand the HPN infusion routine. This training covered all aspects of care: the infusion line (Hickman line), the aseptic technique to connect the administration set to the HPN feed, the connection of this to the Hickman line, as well as the setting up of the electric infusion pump.

5.3.1 Subcategory – maintaining HPN infusion routine

All study participants were dependent on HPN and they continued HPN treatment at home following discharge from hospital. Participants had to manage and maintain their own HPN infusion routine. The pump and bag were placed onto an infusion drip stand. Once this was set up the participant had to carry the bag, infusion pump and drip stand around the house.

Participants who had very high losses from stoma could be on HPN feed for up to seven days per week. Participants described the impact of the infusion routine (and its frequency) on their daily activities:

> *'I don't like being on for twelve hours in here [at home] every day. We have not been able to go away or holiday, you know what I mean stuff like that and I find it quite binding…' P#1.*

'I'm on [HPN] twelve hours a day every other day, and I just could not go anywhere, completely anywhere' P#5.

5.3.2 Subcategory – access to technical help to set up HPN infusion

Most of the participants managed to set up HPN infusion at home. However, a few them needed technical help. One participant had poor vision and very limited hand dexterity. She was dependent on help from her family member who would come to her home and to set up the HPN infusion at night:

'I kept having to fetch my daughter because she just lives across from here right next door she only has a road to cross that's all. I said can you come because I can't do it. I've been at it an hour' P#4.

Another participant had poor eye sight from another chronic health condition. She had help to set up the HPN infusion provided by her spouse:

'My husband puts me on it; I have to take myself off it. I do that because he puts it on at twelve and he has to click the bottom off and it's like a blue fastener, and I find it hard for me to take that off' P#1.

One participant had very poor hand dexterity from a chronic health illness. She lived alone so she became dependent on technical help provided by the home care company. A member of the home care company's nursing team came to her home at night to connect the HPN feed, and in the following morning to disconnect the infusion:

'In my right hand, it's like a claw, and I can't grip and I get ulcers on two of my fingers [index and middle fingers]… and since I am right handed it's very difficult to learn to do things left handed (Laughs) so they didn't think I would be able to do it myself. I have a nurse from X [name of homecare company] coming in five days a week. Just to connect me up and disconnect me [from the infusion pump]. Five days

a week, evening to connect and morning to disconnect. Seven o'clock in the evening and nine o'clock in the morning. Fourteen hours [at night]. Five nights [a week]. I have Wednesday night and Saturday night off. Me, as long as they are not together' P#6

5.3.3 Subcategory – mobility with HPN equipment

An electric infusion pump and an infusion drip stand were required for the HPN feed to be infused safely and correctly. Each participant received training from the home care company on how to operate the infusion pump. The individual must have good hand dexterity and eye sight in order to operate the infusion equipment correctly and safely.

The HPN equipment was smaller and more compact in size than that used on the hospital ward setting. Older participants described the impact of the HPN equipment on their mobility around the house:

'Once you put these bags on at night and you are pulling it around, you get fed up of doing it' P#1.

'It's quite a heavy bag to carry around with you all the time…so I tend to sit in the evenings so that's made quite a difference….it's really restricting you can't go out in the evening' P#3.

These mobility issues around the house were most frequently described by participants who were recently discharged from hospital and were still recovering from their illness.

5.3.4 Subcategory – general health changes

HPN treatment provided the full range of macro- and micro-nutrients which were poorly or inadequately absorbed by individuals with a range of medical conditions. The participants of this study had undergone bowel surgery

which left them with reduced length of small bowel and the formation of a stoma. They were encouraged to continue a restricted diet and fluids in order to maintain stoma output, but they were all dependent on HPN in order to maintain health. Participants described a range of positive general health changes from maintaining HPN infusion:

> *'I'm feeling quite well and I look quite well…and everybody says I look quite well' P#1.*

> *'I'm alive now and I think without it I wouldn't be here…definitely' P#2.*

> *'I'm driving now again and I take the dog out every day for probably a mile, two miles, do my own shopping and everything. I belong to a book club so I meet with them for lunch now and again and friends' P#3.*

> *'It stops me from passing out. I mean I was passing out; I was falling over as if I were… I don't know, you know when you were drunk I suppose…. I was dizzy' P#4.*

> *'I am one of the lucky ones because my heart and my lungs aren't affected so as long as I keep on HPN and what not, I'm not going to die with it' P#6.*

> *'When I see people that I've not seen for a few weeks they tell me that I've put weight on or they'll say, 'Have you put weight on?', you looked like you have put weight on, you look better in your face" P#7.*

> *'So if I don't have HPN I'll die … that was explained to me that HPN is actually keeping me alive' P#8.*

'I have more energy, I wasn't as tired. It has completely stopped me needing blood transfusion as well' P#10.

5.3.5 Actions strategies for maintaining daily activities and social interactions

During discharge planning each participant was given written information about the weekly HPN infusion routine. However, all individuals were advised and encouraged to choose when to set up the HPN infusion in order to fit round their daily activities and social interactions. The intention was to encourage them to maintain daily activities gradually during their rehabilitation at home. Participants described how they achieved this once they had settled into their home environment:

'They let you decide how long you want to have it over but the least time you have is over twelve hours. You can have it during the day or during the night; it's entirely up to you. I like it over twelve [hours] because I'm free the rest of the day' P#8.

'Last night I put it on a little bit early about half past seven so I take off at half past seven. Once day time's here, I am happy you know what I mean …. being able to go out, just taking off when you want' P#1.

One participant was confident in maintaining HPN infusion routine, the individual varied the HPN infusion nights to fit around social engagements:

'I had to change one night because I needed to be up early and I don't want to spend big expanse of time on it [HPN] so I thought I'll give myself a night off. So what I did was I had, as well as having the Monday night off, I also had the Wednesday and Saturday nights off. And then I went back to the normal pattern the following week' P#11.

All the study participants were able to maintain HPN treatment and integrate this into their daily activities gradually as they settled into their own environment. None of the participants interviewed had problems with infection from their central venous catheter, which was used for HPN infusion.

In order to encourage mobility at home and when they were going out, the participants were offered the use a mobile, portable, electric infusion pump which would fit inside a standard size rucksack. Some participants who had used this described their experiences with portable pumps:

> *'I've been using that bag [rucksack] and I've been putting it [HPN feed] in here and I've been carrying it when I gone to the pub … on Saturday night you know when it's not busy, and I can get away with it' P#1.*

> *'The pump is fantastic. It's not obtrusive, it's small and when you got it on in the bag [rucksack], nobody knows that there is a pump in there' P#9.*

During the HPN training programme at the hospital, each participant was assessed by the clinical nurse specialist of the HPN team to see if the individual was able to self-care and to maintain HPN treatment safely and competently at home.

Three of the study participants were found to be unsafe to maintain HPN treatment at home due to their concurrent chronic health conditions: impaired eye sight (one participant), poor hand dexterity (one participant), and a combination of both poor hand dexterity and impaired eye sight (one participant).

One participant was fully dependent on their spouses to maintain HPN treatment:

> *'I can't see with my right eye so my husband puts me on it [HPN] at twelve o'clock' P#1*

One participant was living alone and her underlying chronic ill health prevented her from manipulating the infusion administration set safely or operating the infusion pump accurately. Her close family members were not living in the same city so they were not suitable carers for her HPN treatment. This participant was offered a 5-day a week comprehensive access to technical help to set up HPN infusion at home, provided by the home care company:

> *'Because I've got a condition that causes a thickening of the skin but from inside not outside…I can't use my hands properly. In my right hand, it's like a claw and I can't grip and I get ulcers on my fingers [index and middle fingers]. I have a nurse from the home care company coming in five nights a week' P#6.*

Another participant was also living alone but she had chosen the option of involving her close family members as main carers in maintaining HPN infusion routine. These family members lived on the same street and they received aseptic training from the clinical nurse specialist of the HPN team at the hospital. They also received training on the use and operation of the infusion pump from the home health care company.

> *'I'm diabetic…and they said I've got retinitis…retinopathy sorry. Neuropathy in my feet, I can't feel them…I also got arthritis in my knees. I said to her, S, [clinical nurse specialist for HPN] do you mind if, while you're training me, you train my other daughters-in-law because they will help me' P#4.*

One participant who also had a chronic ill health condition explained that his wife had made the request to be the main carer for maintaining HPN infusion routine. This participant's spouse also provided support and help with stoma care at home:

> *'We're married and it was just she took it on. Oh yes we have discussions about it. I asked her if she's taking on too much and she said no and she just went ahead and to be trained. I don't know really… I just …. She just wanted to do it, and she won't take no for an answer so I just let her do it' P#12.*

5.3.6 Central phenomenon (core category) – living with loss and its connection with HPN

Following discharge from hospital, the participants had to integrate the HPN treatment into their daily activities and social interactions. Some of the participants were living with their spouse or partner, but several of them were living alone. For those who were living alone most of them have siblings who were living in the same city. One participant who was living alone and her older sibling was living in another city some distance away.
One participant who lived with a partner described her night at home with HPN treatment following prolonged hospital stay:

> *'I was relieved to be out of hospital to be able to sit, it was just lovely to be able to put your pyjamas on and watch TV, then the realisation there were still things on-going because I still got the HPN to do so it wasn't just a sit down and relax…' P#7.*

All the participants had to make time for HPN treatment, and this would invariably mean that they had to make adjustments or changes in their home life and social life. The HPN training that they had received at the hospital would not have prepared them for these aspects of reintegration into their own environment:

'So if I'm going out and I get back at half twelve [at night], you've got to put the stuff on at half twelve, it's a bind' P#1.

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'It's hard to think that I have to do all this on my own you know because I live alone' P#3.

Participants who received technical help to set up HPN infusion from home care companies had less flexibility in changing the HPN infusion routine at short notice. This individual declined visitors at home in the evening so that it did not interfere with the technical help to set up HPN infusion provided by nurses from the home care company:

'A nurse from X [home care company] comes five days a week, evening to connect and morning to disconnect…seven o'clock in the evening and nine o'clock in the morning. So, I don't go out or have many visitors in the evening' P#6.

Participants who were maintaining HPN infusion routine independently described their experiences in the loss of choice in how they spent their evenings at home:

'Just the evenings I can't go to theatre or cinema or anything that I used to do now and again with a group of friends' P#3.

'Once I'm connected, it's quite a heavy bag to carry around with you all the time so I tend to sit in the evenings so that's made quite a difference' P#9

Some participants said they were unable to go away because of the need to maintain HPN infusion routine. The amount of HPN infusion equipment which had to be taken on holiday was problematic and the individuals felt a loss of independence and a loss of choice because of this:

'I can't go away for a weekend or even overnight. It's restricting because taking all that with you, I can't see that you can really go away overnight even … because it would be too … too difficult taking the trolley and then all the [HPN] bags and things that you have to take, and the equipment to actually connect and disconnect, and then the stoma bags, disposal everything like that would be very awkward. I don't want to do that I don't think' P#3.

'Why should I have the stuff [HPN infusion] when I'm on holiday? I can't enjoy myself when I got HPN for twelve hours a day. So holidays are non-existent now. It's totally, totally taken over my life since the accident. It just revolves round medications and HPN – that's my life. Sometimes it gets me depressed like now [laugh] when you talk about it, it's depressing' P#5.

Participants disliked the inflexibility with the HPN infusion routine. They described this as the loss in choice in having to maintain HPN infusion routine when returning home late from a night out:

'You come home late, you're tired and you've got to have HPN on. It goes on late into the next day. It's demoralising you've got to have it on all through the night, most of the day as well, and I just hate this stuff' P#5.

Another participant described the loss in choice in leisure activities:

'You do feel like you're on the outside again … that you can't continue with the activity that you were doing before so it does make you feel a little separated and I think it's coming to terms with that' P#7.

Several participants described the loss of independence in order to maintain HPN infusion routine:

'It rules your life. You've got to live around it. It's a case of you live or you die so everything revolved round it' P#7.

'At the end of the day you don't want to die so you've got to have it [HPN]' P#8.

One participant was unable to seek employment because of the health condition:

'I've been told by numerous medical professionals that working, I am going to run myself to the ground and I'm going to kill myself so they have asked me not to work so I was put on disability benefits and incapacity benefits' P#10.

Several participants described the loss of self-image caused by the stoma bag and the HPN infusion line, or the HPN infusion kept inside a rucksack:

'At night you have got the night [stoma] bag on and then you got HPN stuff you know what I mean, you feel a bit… you feel unattractive do you know what I mean, with all this on' P#1.

'I was a bit worried about it at first …what would people think? I was worried about when we went out in the evenings, what would people react when you show them with a bag on my back and the tubes…' P#9.

Participants continued to feel the loss of independence on the basis that they had to maintain HPN treatment in order to stay healthy:

'I haven't got a quality of life no more, compared to what I had before the accident as work, I haven't got a life… and I'm totally dependent on this [HPN] …my medical condition' P#5.

'The feeling of not being all together complete… having to do this [HPN] every night and every morning … just takes its toll' P#9.

'I have HPN five nights a week and it runs over twelve hours. On dialysis day, I go on it [HPN] say six o'clock at night, so at six o'clock the next morning. I take myself off it or my wife will take me off it. Then I have to be at the renal dialysis unit for eight o'clock … so that was Monday, Wednesday and Friday' P#12.

Some participants needed help from others to maintain HPN infusion routine. They described their loss of independence:

'My niece who is a district nurse – she did a hell of a lot with the HPN because she was really concerned… and I get tired really quickly' P#5.

'I won't be here if it wasn't for my wife I'll be honest. She just took it upon herself to learn and to train to do HPN. She also did me stoma, she just got stuck in' P#12.

Participants who started the HPN infusion in the evening described the loss of mobility around the house:

'I have to carry it all night, if I go to the kitchen, I have to carry it, I want go upstairs I got to carry it upstairs. I'm just tired of it…' P#1.

Participants described the practicalities of having to take the HPN feed, infusion pump with them when they went to empty the stoma bag:

'You go to the toilet to empty stoma and you're carrying that [HPN bag, pump and drip stand] to toilet' P#3.

The weight of the HPN bag and the infusion pump were problematic to one participant:

> *'It's two thousand … two litres two hundred [millilitres]. It's very, very heavy … very heavy when it's full and you have carried this as well as the pump' P#9.*

Participants experienced increased self-consciousness with the HPN feed and infusion pump contained inside a rucksack when they were in social situations:

'At Friday night or Saturday night we go down to the Park Hotel and there is a lot more people, and it's a lot more noticeable and I don't feel comfortable putting this [rucksack containing the HPN bag and portable infusion pump] here. You feel more noticeable, and you've got the wire [Hickman line]' P#1.

One participant described what happened when someone asked about the rucksack which contained the HPN feed and infusion pump:

> *'You get people looking …. I went to the pub to pick up my partner' dad and I walked in and it [rucksack containing HPN feed and portable infusion pump] was on my back. He just turned to me and said, 'Have you been to the gym?' – this was the landlord. I said no, so I explained it was my feed and what it was, and what it was for' P#10.*

All the study participants had to maintain stoma output and to maintain HPN treatment. They described how they lived with these two health interventions at home on a typical day:

'I can cope with the stoma but there's nothing I can do about the HPN. I've got to be here [at home] to do it. I do miss out somehow… I think the HPN is the worst' P#3.

'When you go to bed you got the stoma and you got the HPN as well, your sleep is disturbed so much you are either going to empty the stoma, or I think I've got to go and empty it I'm so conscious of it leaking that every time it's filling up a little bit, I must go or the HPN makes you want to go to the toilet. So on HPN night, it's a double whammy – it's not just the stoma, it's the HPN as well' P#7.

'Having HPN is very restrictive but I think you can actually live with it if haven't got a stoma as well' P#8.

5.3.7 Summary on category HPN

All the participants learnt how to maintain HPN infusion routine from the clinical nurse specialist for HPN. They were competent in connecting the HPN feed to the Hickman line, and then connecting the bag to the infusion pump. Following discharge from hospital all the participants had to learn to integrate HPN treatment into their daily activities. Some of them were able to maintain HPN infusion routine safely and independently. Others were offered technical help to set up HPN infusion, and this was provided by nurses from the home care company on set days of the week.

The study participants' experiences during rehabilitation at home were rich in descriptions of what they could and could not do at home and in social situations. Participants described a range of positive and negative experiences living with HPN treatment. These positive experiences were associated with the general health changes. Their negative experiences were related to aspects of the need to maintain HPN infusion routine in terms of the long infusion time and its frequency, and the issues around mobility with HPN equipment at home, in social situations and when on holidays.

5.4 Chapter summary

The findings discussed in this chapter demonstrated that participants had to learn how to integrate both the stoma care and HPN treatment into their daily lives during rehabilitation at home. All the participants experienced a range of positive and negative general health changes which were closely associated with their ability to maintain stoma output and to maintain HPN infusion routine. A couple of the study participants had described feeling depressed. They referred to the overall impact on their lives as the result of having a stoma and becoming dependent on HPN treatment. The issue of depression was not raised by the other participants.

The criteria proposed by Corbin and Strauss (2008) were used to evaluate the causal conditions stoma care and HPN treatment, and the action strategies in order to refine and define the core phenomenon. The findings revealed that participants experienced a sense of loss in a range of daily activities and social interactions. Therefore, the central phenomenon living with loss was closely linked to the participants' ability to maintain stoma output, and to maintain HPN infusion routine. The consequences of using these action strategies successfully would be to reduce the intensity of living with loss in daily activities and social interactions.

Chapter 6 DISCUSSION AND CONCLUSIONS

6.1 Introduction to chapter

The aim of this grounded theory study was to generate theory that explains the experiences of adult patients living with HPN and complex medication regimens. Chapter 4 explained the generation of the central phenomenon living with loss from interview data provided by the participants (See Chapter 4 Figure 4 Connections between the core category living with loss and the other categories and subcategories). Chapter 5 Sections 5.2 and 5.3 demonstrated the data to explain the relationship between the subcategories and the core category. It also revealed that participants experienced a sense of loss in a range of daily activities and social situations (see Chapter 5 Section 5.2.7 Summary on category stoma and Section 5.3.7 Summary on category HPN). This chapter focuses on the discussions of this theory, using published literature to explore the relevance and trustworthiness of the findings. The implications of the theory for local practice development will also be discussed and integrated into the relevant sections. This is followed by discussions on the strengths of the research process and the limitations of the study design; and finally the implications of findings for national practice and for future research.

Early published literature on patients treated with HPN was focused on the clinical outcome and mortality of these patients (Jeejeebhoy et al., 1976 p.32, Greig et al., 1981, Rault and Scribner, 1977, Fleming et al., 1980, Byrne et al., 1979) and these publications have been discussed in chapter 2. Since the 1980s the QoL of patients receiving HPN has been assessed using a range of standard instruments which were not specific for HPN treatment (Herfindal et al., 1989, Carlsson et al., 2003, Ladefoged, 1981, Detsky et al., 1986, Bergner et al., 1981, Jeppesen et al., 1999, Pironi et al., 2004, Persoon et al., 2005). Only two of these studies included information about the presence of a stoma in patients receiving HPN (Jeppesen et al., 1999,

Persoon et al., 2005). It remained unclear if the presence of stoma influenced the QoL of patients receiving HPN. There is a paucity of published research in relation to the experiences of patients with a stoma receiving HPN.

The published literature referred to in the following sections was identified from the literature review which was discussed in chapter 2. The original literature search was updated during the process of data analysis when the category stoma and subcategories maintaining stoma output, access to toilets, managing dietary changes and changes to general health were being refined and defined. This additional literature search was carried out using the same databases, and it generated a small number of published research studies on patients with a stoma. These studies on patients with a stoma and the literature on patients receiving HPN were used to refine and verify the theory of living with loss.

6.2 Defining and verifying the theory of living with loss

In chapter 4 I described how the theory of living with loss emerged from the participants' experiences when integrating and maintaining stoma care and HPN treatment at home and in social situations following discharge from hospital (see Chapter 4 Section 4.3.16 Connections between the core category living with loss and the other categories and subcategories). In the following sections, published literature on patients with a stoma receiving HPN will be used to explore these connections in order to support the theory of living with loss.

From the analysis of the findings, I proposed a theory that participants experienced the sense of living with loss when integrating the need to maintain stoma output and to maintain HPN treatment at home and in social

situations after discharge from hospital. The interview data illustrated that the intensity of living with loss was associated with stoma, which in turn was influenced by the high volume of watery stoma output, the medications to reduce losses, the access to toilets, the restrictions on diet and fluids, the loss of choice, self-image, independence, job, as well as the increased self-consciousness (see Chapter 4 Figure 2 Relationships within focused codes on stoma and Figure 5 Visual representation of the process developed during data analysis for stoma).

For HPN the central phenomenon of living with loss was influenced by the need to maintain HPN infusion routine**,** the impact of HPN equipment on mobility and the access to technical help to set up HPN infusion (see Chapter 4 Figure 3 Relationships within focused codes on HPN and Figure 6 Visual representation of the process developed during data analysis for HPN)**.** Each of these subcategories which were associated with stoma and HPN will now be discussed in the following sections. These salient points will be discussed further in order to illustrate how the findings of this grounded theory study have contributed to the existing knowledge about the experiences of patients treated with HPN ~~and~~ living in the community.

6.3 Relationships between living with loss and maintaining stoma output

In chapter 5 the findings supported the lack of control with high stoma output (see Section 5.2.1 Subcategory maintaining stoma output) as the main factor which contributed to the participants' sense of loss of choice**.** The intensity of this loss of choice was associated with the restrictions on diet and fluids (see Section 5.2.4 Subcategory general health changes) in order to maintain stoma output. These findings were consistent with those reported in a Swedish interview study conducted by Carlsson et al. (2001), who explored

the experiences of patients who were living with a stoma and short bowel syndrome associated with Crohn's disease.

All six participants in the Swedish study experienced watery stoma losses greater than 2 litres a day. They had to empty the stoma between 8 to 15 times a day. Participants carried extra clothing with them when going out in case of unexpected leaks from stoma. The Swedish researchers concluded that the *'unpredictability of stoma bag changes'* caused limitation in the social life of patients who suffer from short bowel syndrome, and have a stoma (Carlsson et al., 2001 p.96).

Amongst the findings discussed in chapter 5 (see Sections 5.2.1 Subcategory maintaining stoma output), was the notion that several of the study participants refrained from some social interactions in case the stoma bag leaked or they needed frequent access to toilets (see Section 5.2.2 Subcategory access to toilets). This demonstrated that the participants' sense of living with loss was intensified by the loss of choice in places that they could visit which offered easy access to toilets (see Section 5.2.5 Action strategies for maintaining daily activities and social interactions). Similar findings were also reported in Carlsson's study (Carlsson et al., 2001) whereby patients had a preference to visit places *'with high sanitary standards'*, which in turn reduced the choice of places when going out.

All the participants in this current grounded theory study described the necessity for access to toilets frequently in order to empty stoma bags. Their experiences with stoma leaks and accidents remained troublesome, despite the participants' compliance with the restrictions on diet and oral fluids and the use of medications to reduce losses. The patients who were interviewed in Carlsson's study (Carlsson et al., 2001) reported a variation in the efficacy

of medications to reduce stoma output; their experiences with restrictions on diet and fluids suggested that these were more effective in reducing stoma output.

When they were in hospital all the participants in this current study were given advice and written information about restrictions on diet and oral fluids by the Sheffield HPN team. Participants were offered low residue diet menus on the wards to support the need to maintain stoma output when they were learning to empty the stoma bag and to look after the skin site. ~~While a~~

All the meals ~~food was~~were delivered to them on the wards. ~~, t~~They did not need to think about how they might incorporate these dietary changes into their everyday life until after they had returned to their home environment.

During this current study the research interviews revealed that several participants described how they had chosen to eat what they really liked instead of what they should have once they were discharged from hospital. These individuals understood the reasons for the dietary advice given to them by the Sheffield HPN team. ~~, but t~~They described their dislike for the lack of taste and limited choices offered by the low residue diets. Participants were aware of the potential of these foods to cause high stoma output, but they had chosen to satisfy their own desires by enjoying the foods that they really liked. They were prepared to deal with consequences of high stoma output, and the inconvenience of stoma leaks and accidents.

These participants' sense of loss in choice was similar to that reported by an American postal questionnaire study which asked over 40,000 patients with stomas about food choices and avoidances imposed upon them because of their stoma (Floruta, 2001). From the 604 replies received by this American

researcher, over 88% of the respondents did not follow the dietary advice given to them for the stoma; over 11% of respondents indicated that they had accepted the dietary advice and had modified their diet; and just over half (55%) of them were following the special diet closely and indefinitely. This researcher also summarised the comments from 201 respondents who described their non-adherence to dietary advice. The overall impressions from these respondents' quotes reflected the individuals' desire to have control over what they could eat and drink; their preference of trial and error with foods, and their willingness to deal with the effects of these on the stoma output.

Floruta (2001) acknowledged that in their study the dietary advice provided by healthcare professionals showed variations and inconsistency, and there was a lack of published studies which examined the effect of different foods on stoma output. Similar findings were generated from participants who were interviewed in this current grounded theory study, supporting the need for more information and the opportunities for prospective research studies to define the dietary and oral fluids advice for patients with a stoma. The availability of reliable dietary information to maintain stoma output had the potential to reduce the sense of living with loss in patients with a stoma.

All twelve participants in this grounded theory study were receiving HPN. This represented a close relationship between the changes in general health and the extent of malabsorption and malnutrition caused by the high stoma output**,** despite the participants' compliance with medications and adherence to dietary advice in order to reduce stoma losses. Participants described the tiredness they felt during the day was caused by the disrupted sleep associated with the need to empty their stoma bag frequently at night. These negative changes in general health also affected the participants' abilities to carry out daily activities such as house work and shopping. These findings

were consistent with those reported in Carlsson's interview study, whereby the Swedish patients described the need to empty stoma bags at night as being the reason for the '*fatigue which interfered with daily activities'* (Carlsson et al., 2001 p.103).

The patient self-help group, 'Patients on intravenous and nasogastric therapy' (PINNT) does not offer dietary advice to patients with a stoma receiving HPN. One manufacturer who produces stoma bags and skin barrier appliances states in their patient information brochure that there is no need for a special diet for patients with a stoma. This advice is contrary to that given by Sheffield HPN team to patients with a stoma receiving HPN prior to discharge from hospital. The NHS Choice website offers limited information and general advice on diet and oral fluids for patients with a stoma (NHS Choices, 2014).

In summary, the findings from this grounded theory study have demonstrated that the connections between these subcategories: restrictions on diet and fluids, access to toilet and changes to general health support the participants' desire to maintain stoma output by minimising or preventing stoma leaks and accidents in their daily activities and social interactions.

During their hospital stay patients with a stoma are given dietary advice in the form of a written patient information leaflet. There is not much published research data on the efficacy of dietary restrictions. Therefore, the information given to the patients is poor. This was shown by some of the study participants who felt more loss because of the restrictions.

6.4 Relationships between living with loss and the loss of independence, job, self-image, increased self-consciousness

All the participants in this study had made satisfactory improvement in their physical health during the time they were receiving training to manage stoma care and HPN treatment in hospital. Following discharge from hospital, each individual had to learn to be independent ~~again~~ and to self-care for the first time.

From the interview data provided by the participants, the negative changes in general health such as malabsorption and malnutrition caused by high stoma output (see Section Chapter 5 Section 5.2.4 Subcategory general health changes), were noted from the participants' comments on having difficulties in carrying out simple daily tasks associated with self-care and housework. Participants who were living with a spouse or partner became dependent on their help and support with a range of activities, both at home and when going out. (see Chapter 5 Section 5.2.5 Action strategies for maintaining daily activities and social interactions)

These negative general health changes illustrated the loss in independence, which in turn appeared to increase the intensity of the sense of living with loss during the early stage of rehabilitation at home. The findings from this grounded theory study were consistent with those reported by Carlsson et al. (2001) whereby their patients described *'reduced strength and severe fatigue as the cause for not being able to do housework, take part in family activities and enjoy social life'* (Carlsson et al., 2001 p.100). This similarity has illustrated the close relationship between stoma care and HPN treatment in the study ~~is group of~~ participants.

3 participants in this grounded theory study had a job before they became ill~~,~~ ~~but t~~The loss of employment was described by all ~~3~~ of them at the time of the research interviews (see Chapter 5 Section 5.2.6 Central phenomenon living with loss and its connections with stoma). The loss of employment reported by these 3 participants was associated with the reduced physical strength as the result of negative changes in general health**,** and the need to maintain stoma output. These participants' sense of living with loss was intensified by the loss of employment. These findings from this study showed similarities to those reported in Carlsson's study whereby four out of six patients with a stoma were treated with HPN, two of them had to leave their previous employment, whilst the other two were unable to continue with full time employment due to fatigue and reduced physical strength. Patients from this Swedish study described the main reason for the loss of job was the *'time needed to manage the stoma and to maintain HPN'* (Carlsson et al., 2001 p.101). The similarity in the experiences of the participants from this study and those reported in Carlsson's study supported the notion that the negative impact from stoma losses placed significant burden on individuals' physical health. The time needed to maintain HPN treatment was not described by the participants in this study as a main cause for loss of ability to maintain or continue employment.

The loss of body image experienced by patients who had undergone stoma surgery has been studied by researchers since the 1960s (Orbach and Tallent, 1965, Persson and Hellstrom, 2002, Aronovitch et al., 2010). One study reported that the loss of body image persisted after the patients' initial surgery with the formation of a stoma (Sharpe et al., 2011). From the analysis of interview data generated in this grounded theory study, all the participants described the sense of loss of choice in having to wear loose fitting clothes in order to disguise the stoma bag. Some study participants experienced the sense of loss in self-image when they had to wear dark coloured clothes in order to disguise stoma leaks or accidents, and they had

to carry spare clothing with them when going out (see Chapter 5 Section 5.2.5 Action strategies for maintaining daily activities and social interactions). The study participants did not describe the impact of having a stoma on their body image. This contrasted with the findings reported by other researchers who studied patients who had undergone stoma surgery.

Although these study participants were being resourceful in adopting measures to lessen the burden and anxiety from stoma leaks, they continued to experience increased self-consciousness in social situations. These findings were consistent with an Australian interview study of patients with a stoma whereby the *'stoma undermines self-esteem and body image'* in the event of accidental leaks (Manderson, 2005).

The theory generated from this study demonstrated that patients with a stoma (see Chapter 5 Section 5.2.6 Central phenomenon living with loss and its connections with stoma) and treated with HPN (see Chapter 5 Section 5.3.6 Central phenomenon living with loss and its connections with HPN) experienced a sense of living with loss when making adaptations at home and in social situations in order to maintain stoma care. The impact of maintaining stoma output**,** the loss in self-image and the increased self-consciousness experienced by the participants of this study have not been reported by previous studies which assessed the QoL of patients receiving HPN.

From the analysis of the interview data in this grounded theory study, one participant continued to experience an intense sense of living with loss following discharge from hospital. This individual remained house-bound with self-imposed social isolation avoiding most social interactions. The study participant's relationship with the stoma echoed those reported in

several research studies which showed that after discharge, some patients continued to experience psychological distress associated with the formation of the stoma, in particular the loss of control with stoma losses, the loss of body image and restrictions on social activities (Popek et al., 2010, Knowles et al., 2013).

The Sheffield HPN team has ~~runs~~ outpatient clinics for patients receiving HPN every four weeks. The implication for local practice of the findings from this study is that the patients' experiences of living with loss could be explored during follow up visits at the HPN clinic, in addition to consideration of the positive changes in general health gained from maintaining HPN treatment. The opportunity to provide home visitation to selected patients who continue to experience the intense sense of living with loss could be considered. These patients could be offered on-going counselling and support, or in severe cases the individuals might benefit from specialist psychosocial care in order to help them to cope with the stoma-related challenges in everyday life and to improve their quality of life.

6.5 Relationships between living with loss and maintaining HPN treatment

All participants were dependent on HPN treatment in order to overcome the problems of malabsorption and malnutrition from oral diet as the result of bowel surgery and the formation of a stoma. The interview data provided by these participants supported the positive changes in general health associated with HPN treatment (see Chapter 5 Section 5.3.4 Subcategory general health changes). These findings were consistent with published studies which assessed the QoL of patients receiving HPN, and these have been previously discussed in the literature review in chapter 2.

From 1980s to 2010 the published quantitative research studies which assessed the QoL of patients receiving HPN used a range of QoL instruments such as quality adjusted survival (Detsky et al., 1986), generic or disease-specific sickness profile (SIP) (Bergner et al., 1981), short form health survey (SF-36) (Carlsson et al., 2003, Pironi et al., 2004), all of which were non-specific for patients receiving HPN. The outcome findings from these early studies were criticised for their relevance to patients receiving HPN because the researchers ~~had~~ used a range of QoL instruments which had not been validated for patients treated with HPN. Furthermore, these QoL studies did not have information on the presence of a stoma in ~~the~~ patients receiving HPN. There are currently no published studies that provide a detailed insight into the experiences of patients with a stoma receiving HPN.

The experiences of the study participants with the loss in self-image, the increased self-consciousness, and the loss of mobility (see Chapter 5 Section 5.3. 6 Central phenomenon living with loss and its connection with HPN) were consistent ~~to~~ with some of the psychosocial problems reported in a Dutch study of 48 patients receiving HPN (Persoon et al., 2005). This Dutch study combined the techniques of questionnaires and interviews and the researchers reported the following problems due to HPN: *'fatigue, poor sleep quality, anxiety, depression, lack of freedom, unable to work, being dependent, social impairment in various social activities, problems with mobility, being bound to the pump and housebound'* (Persoon et al., 2005 p.307-308). In this Dutch study only 14 out of ~~forty-eight~~48 patients receiving HPN had a stoma, and it did not explain if there were differences in the extent and range of psychosocial problems experienced by patients receiving HPN with a stoma and those without a stoma.

Two of the published studies identified during the literature search on patients receiving HPN, included patients with a stoma (Jeppesen et al., 1999, Persoon et al., 2005). In one of these studies patients with a stoma receiving HPN reported a lower score for QoL, and these patients were having problems with the fear of stoma leaks and altered body-image (Jeppesen et al., 1999). In Jeppesen's et al (1999) study these HPN patients with a stoma also experienced greater restrictions on daily life with regard to social and leisure activities (Jeppesen et al., 1999 p.844). These findings on psychosocial problems were similar to those generated from the participants in this grounded theory study (see Chapter 5 Section 5.2.6 Central phenomenon living with loss and its connections with stoma).

In 2010 Baxter et al. published a specific instrument which assessed the quality of life of patients receiving HPN (HPN-QOL) (Baxter et al., 2010). This 49-point questionnaire consisted of single or multiple items, and it used either functional scales or symptom / problem scales. All the questions were about HPN and it only had two questions on stoma care: '*the problems in caring for the stoma'* and '*the problems with stoma site'* (Baxter et al., 2010 p.140). These researchers used interviews and focus groups to generate the items and wording for use in the HPN-QOL questionnaire. However, this instrument did not assess the impact of maintaining stoma output on the individual's daily activities and social interactions. The original literature review for this study was updated and this included a small number of research studies which involved patients with a stoma but they were not treated with HPN.

The findings from this grounded theory supported the theory of living with loss, which was illustrated by the analysis of interview data on ~~provided by~~ the participants' experiences in maintaining stoma output (see Chapter 5 Section 5.2.6 Central phenomenon living with loss and its connections with

stoma) and maintaining HPN infusion routine (see Chapter 5 Section 5.3.6 Central phenomenon living with loss and its connections with HPN). The central phenomenon of living with loss was consistent with published literature on patients with a stoma identified from the updated original literature review. Therefore, it would seem appropriate to consider the practical and psychosocial aspects of maintaining stoma output and maintaining HPN infusion routine when designing the items for the assessment of QoL of patients with a stoma receiving HPN.

6.6 Model for living with loss

In healthcare settings patients may experience grief in relation to either chronic illness or sudden ill health. The actions, interactions and emotions displayed by the ~~se study~~ participants of the current study resonate with some aspects of the Kubler-Ross's model (Kubler-Ross, 1970), of the five stages of grief, in the context of maintaining stoma (see Chapter 4 Figure 2 Relationships within focused codes on stoma and Table 16 A paradigm model for the category stoma) and HPN (see Chapter 4 Figure 3 Relationships within focused codes on HPN and Table 17 A paradigm model for the category HPN).

6.6.1 The Kubler-Ross model

This model was described by an American psychiatrist Elizabeth Kubler-Ross in her book *'On Death and Dying'* (Kubler-Ross, 1970) when she was working with terminally ill patients. She later extended her model of grief to any form of catastrophic personal loss such as the loss of a job or income, major rejection, divorce, drug addition, the onset of a disease or chronic illness, as well as tragedy and disasters. The five stages of grief in this model are also known by the acronym DABDA and these are described in Table 19.

These five stages of grief do not occur in a specific order. The model is not intended to be used as a checklist for emotions which could be or are likely to be felt by the individual. Kubler-Ross' hypothesis of this model is based on the premise that an individual who experiences a life-threatening or life-altering event may not feel all five of the responses because each individual reacts to personal losses differently (Kubler-Ross, 1970). The model of grief provides the conceptual framework from which the theory of living with loss generated from the study participants' data could be best described. From the analysis of interview data, the study participants demonstrated the following stages of grief: bargaining, depression and acceptance when living with stoma ~~care~~ and HPN ~~treatment~~. The intensity of denial and anger varied amongst the study participants (see Chapter 4). Hence, there is no reason to expect the analysis of the interview data to provide a perfect match to all stages of the model.

Table 19 The Kubler-Ross Model or the five stages of grief (~~Kübler~~Kubler-Ross, 1970)	
Stage 1 Denial	As the reality of loss is hard to face, denial is the first reaction to follow the loss; individual develops a false reality;
Stage 2 Anger	Feels anger with himself / herself or others; feels resentful with the notion of 'why me? It's not fair';
Stage 3 Bargaining	Feels partial acceptance acknowledging what has happened cannot be undone;
Stage 4 Depression	Finds the idea of living pointless and may become silent refusing visitors; followed by feelings of sadness, regret, fear, and uncertainty when accepting the situation;
Stage 5 Acceptance	Comes to terms with inevitable future or tragic event with a calm and stable ~~mindset~~mind-set.

6.6.2 Living with loss

The theory of living with loss generated from the interview data provided by the study participants' experiences with stoma care and HPN treatment (see Chapter 4 Figure 4 Connections between the causal conditions, central phenomenon (core category) living with loss and the other categories and subcategories) mirrored some stages of the Kubler-Ross model. The current study findings illustrated the participants' feelings of sadness, regret and uncertainty when accepting their own situations of living with the stoma and managing HPN. ~~treatment.~~ They accepted that what has happened to their health could not be undone. They came to terms with the reality and this was illustrated by their involvement in maintaining stoma output and HPN infusion routine.

The ~~ir~~ effort to reduce stoma output in order to reduce leaks and accidents reflected the study participants' acknowledgement of what had happened, and they were accepting their own situations (see Chapter 5 Sections 5.2.1 Subcategory maintaining stoma output and 5.2.2 Subcategory access to toilets). One participant remained in the stage of depression with social isolation and this could be due to the individual's own reaction to the sudden illness. The interview data from this study did not demonstrate denial as the participants had been living with stoma and HPN for some time before they were interviewed. However, the expression of anger was evident from one participant who had suffered a sudden and life-threatening illness.

The findings from this small scale study have illuminated the need for recognition of the patients' physical and social wellbeing when they live with the two health interventions: stoma care and HPN treatment following discharge from hospital. The generation of the theory living with loss was

supported by the Kubler-Ross model, and it answered the central research question of this study, making a contribution to the knowledge about patients' experiences living with HPN in the UK.

6.7 Strengths of the research process

This study ~~also~~ demonstrated the inclusion of a diversity of participant characteristics (see Appendix 15), making these findings relevant to patients with intestinal failure ~~short bowel syndrome~~ receiving HPN. The strengths of the research process have been assessed using the Cabinet Office document 'Quality in Qualitative Evaluation: A framework for assessing quality in qualitative evaluation' (Spencer et al., 2003) and this analysis is presented in Appendix 16.

This research study has followed the grounded theory approach (Glaser and Strauss, 1967) with the use of simultaneous data collection ~~-~~and analysis, theoretical sampling (see Section 3.6), and a range of coding techniques (see Section 4.3). The generation of the theory of living with loss was supported by the analysis of the interview data provided by study participants who are living with stoma care and HPN treatment.

6.8 Issues with data collection and analysis

The use of respondent validation, or member checking, involved the cross-checking of interim research findings by the participants, and asking them to verify these in order to demonstrate validity in a qualitative study (Mays and Pope, 2000, Silverman, 2011). This would involve the researcher showing the analysis of the interview data to the participants and asking them to verify that these findings generated from the analytic processes reflected their own experiences with HPN (Kvale, 2007).

However, this study did not incorporate the process of respondent validation and this could be seen as a limitation. The main focus of this study was to explore the experiences of patients receiving HPN. All the interviews took place within a period of fourteen months, so there was a long gap between the first and the last interview. During each interview the participant provided a detailed personal account of maintaining stoma care and HPN infusion routine at that time. The individuals' emotions and lived experiences may have changed by the time the analysed data was presented back to them for respondent validation. The participants might not recall fully what they had said during the interviews. In qualitative healthcare research the use of respondent validation is more suited to action research projects with researchers working with the participants to facilitate change (Barbour, 2001 p.1117).

6.9 Researcher subjectivity and experience

The techniques used in asking questions in a research interview were very different from those used by the researcher during clinical consultations as a non-medical prescriber for in-patients who required parenteral nutrition. The fundamental differences between consultation with a patient and the qualitative interview of a patient as study participant have been highlighted by Britten et al. (1995). The aim of the qualitative interview was to understand the participant's own experiences and meanings rather than imposing those of the researcher's (Britten et al., 1995). However, in both settings the emphasis was to facilitate discussion without causing any harm to patients and participants.

I was aware of this learning need and had consulted primary references written by qualitative researchers on how to conduct research interviews

(Kvale, 1996, Kvale, 2007). I had taken steps to ensure that the interview process did not become a clinical consultation. A semi-structured interview guide containing questions and probes was used to guide the conversation between the researcher and the study participants. The researcher remained mindful and focused on the purpose of the research interview which was to explore the lived world of participants in context of their experiences with HPN (Kvale, 1996).

As the study progressed, I developed confidence in the art of asking questions and listening to the participant's spoken words, as well as in the handling of participant's emotions when they disclos~~ing~~ed sensitive or stressful events and situations. Each interview audio-tape was transcribed verbatim by the researcher. The transcript was checked by the researcher's academic supervisors, who provided feedback on the interview, including the demonstration of sensitivity by the researcher, and on the balance of dialogue between the researcher and the participants. This self-directed learning process ensured that the researcher developed an appropriate style of asking questions whereby ~~to ensure that~~ the interview did not become a clinical ~~c~~consultation.

During the interviews the participants were free to express and describe their experiences without undue influence from the researcher. The researcher used the semi-structured interview guide to ensure that the conversations stayed focused. During the interview the researcher adopted an active listening role, ensuring that any ambiguity noted would be clarified by the individual (Kvale, 1996 p.132). Throughout all the interviews the researcher maintained a value-neutral approach, making no attempts to ask leading questions which might favour a particular outcome, categories or subcategories.

Throughout the data collection stage, I had regular meetings with the academic supervisors to discuss the progress of the research study. During one of these meetings I shared with them my own emotions when encountering a tearful participant during the interview process. I was encouraged to talk about what I found upsetting. These experiences helped me to become sensitised to the issues described by the participant. I realised that I had to remain sensitive and sympathetic without being emotional during the interview. Having encountered this experience early on in the data collection process, I became mindful of the participants' emotions without getting upset. Having reflected on this experience as a researcher, I gained confidence in remaining calm and composed when participants became tearful.

I introduced myself as the researcher when I visited each participant at home for the interview. The inclusion of my job title, consultant pharmacist, on the invitation letter (see Appendix 3) was for information only. At the Sheffield HPN out-patient clinic none of the patients asked about my job title, so it did not appear to have influenced their decision from taking part in this research study.

6.10 Summary of research process and study design

This small scale exploratory study was my first attempt in conducting healthcare research using the interview technique to collect data from patients receiving HPN. I have taken all the necessary steps to ensure that the theory generated from the participant data was credible and trustworthy. I have also taken into considerations the framework for assessing qualitative research (Spencer et al., 2003). The rigor of the research process and the study design has been discussed in Appendix 16. I have identified and

addressed the limitations associated with this study, giving readers the opportunity to assess the validity of the research process used in data collection and data analysis, and the trustworthiness of the theory living with loss.

6.11 Conclusions

The theory of living with loss was generated by the use of the grounded theory methodology in this study, which explored the experiences of patients living with HPN. The analysis of data and the findings provided a rich insight into the participants' everyday life in maintaining stoma care and HP~~H~~N ~~treatment~~treatment. The theory demonstrated that patients with a stoma receiving HPN had to make significant adjustments and changes in their daily activities and social interactions as they settled into their own environment following prolonged period of hospital stay. All the participants experienced a sense of living with loss when ~~in order to~~ maintaining stoma output and HPN infusion routine, which in turn pervaded other aspects of their lives. The intensity and permanency of living with loss differed between participants, and these variations have been demonstrated from the interview data provided by the participants.

All the study participants experienced positive general health changes from maintaining the HPN infusion routine. Once at home participants ~~atients~~ developed a set of strategies which helped them to maintain daily activities and social interactions. The need to maintain stoma output placed persistent and constant constraints on the participants, who had to follow ~~a list of~~ dietary restrictions and to access toilet ~~facilities~~ frequently. The demands from maintaining stoma output increased the intensity of living with loss as the participants had to plan their daily activities and social interactions around stoma care.

Some participants receiving HPN required technical help to set up HPN infusion at night. This help was provided by spouse, partner or close family members. ~~; but i~~In several cases the ~~patients~~ participants were dependent on nursing input from home care companies who delivered the HPN feeds and equipment. The ~~patients~~participants' sense of living with loss from the need to maintain the HPN infusion routine had been reported by earlier studies which used a range of quality of life instruments.

In conclusion, this was the first qualitative study which explored the patients' experiences with both stoma care and HPN treatment in the UK. These study participants have provided valuable information and insight on the impact and influences of these two health interventions on their physical health and social wellbeing, as well as the strategies that they had developed in response to the losses experienced in their everyday lives.

This study has shown that some elements of living with loss were consistent with those published in quantitative and qualitative research studies which assessed the quality of life of patients with a stoma, and those of patients with a stoma receiving HPN. The generation of the theory living with loss answered the central research question of this study, making a contribution to the knowledge about patients' experiences living with HPN in the UK. The theory of living with loss generated in this study resonates with the Kubler-Ross Model of the five stages of grief (Kubler-Ross, 1970).

6.12 Implications of findings for professional practice (Holloway and Walker, 1999)

Holloway and Walker outlined the importance of exploring the implications of research findings in relation to professional practice (Holloway and Walker, 1999). Patients receiving HPN were reviewed by the Sheffield ~~local~~ HPN ~~nutrition support~~ team at regular outpatient clinics. During this ten minute consultation the focus was on the individual's physical health and clinical outcome, and these were assessed objectively using weight scale and clinical chemistry blood tests. The theory generated from the interview data and the findings from ~~in~~ this small scale exploratory study have implications for practice by the ~~local~~Sheffield nutrition support team and other healthcare professionals during the patient's hospital stay. Some of the findings from this study might be considered by local GPs and community nursing teams once these patients have been discharged from the hospital. These implications for local practice in secondary and primary care will now be discussed.

Whilst in hospital, patients with a stoma who needed to continue with HPN were given training, support and information from a range of healthcare professionals working in different clinical teams. The stoma care nurse specialists provided training and support on stoma care. For the HPN infusion ~~routine~~, the patients received training from the Sheffield HPN clinical nurse specialists. ~~of the local nutrition support team.~~ The implication of these findings on local practice is that there is an opportunity to review the dietary advice and information provided by the nutrition support team. ~~to patients with a stoma receiving HPN.~~ Healthcare professionals may wish to consider working more collaboratively in guiding patients to interpret written information on dietary advice so that they understand the relevance of the information available from different sources in the context of maintaining stoma output.

This has influenced my clinical practice during regular parenteral nutrition rounds. As a non-medical prescriber my main role is to review and prescribe the patient's parenteral nutrition. During each consultation I am now also assessing the patient's compliance with advice on dietary changes and ~~new~~ oral medications to maintain stoma output. The NST is best placed to provide continuing advice, support, assessment and encouragement to ~~the~~ patients prior to discharge. I also monitor these patients' progress in terms of their~~have noticed that the patient gains~~ compliance and confidence ~~nfidence~~ when incorporating dietary changes and medicines in order to maintain stoma output during their hospital stay. ~~at home and in social situations.~~

During the in-patient discharge planning process, the Sheffield HPN team assessed each patient ~~was assessed ff~~or competency in maintaining ~~stoma care and~~ HPN. ~~infusion routine prior to discharge.~~ The patients' ~~-~~social wellbeing was not evaluated ~~assessed~~ by any healthcare professionals. There was a general assumption that the patients' competency with stoma care and HPN would equate to the individuals' ability to incorporate these two health interventions into their daily activities and social interactions. ~~There were expectations from healthcare professionals that the patients' spouse, partner and close family members would provide help to the individuals in order to maintain social wellbeing once they had returned home. In light of the findings from this small scale study, the HPN team could be more is proactive in involving the patient's partner, spouse or family members as early as possible when discussing the duration and intensity of practical and social support the HPN patient needs at home. This would has facilitate the discharge planning process by identifying the need for additional nursing care and support to be provided by the home care company which compounds the HPN feeds and delivers the infusion equipment.~~

This study has highlighted new knowledge on the participants' sense of living with loss when making adaptations and adjustments to their life. It remained unclear who was responsible for assessing and monitoring the patients' social wellbeing ~~before~~ after discharge from hospital~~.~~. The theory generated from this study suggested that there were ~~might be~~ opportunities for the nutrition support team ~~members,~~ ~~and~~ the stoma care nurse specialists and the primary care team to evaluate the ~~to extend the range of support and advice to include~~ social wellbeing ~~to~~ of these patients following ~~during their~~ prolonged stay in hospital. Further work would be required to assess what ~~how these~~ pre-emptive measures and how these could have the potential effect of reducing the patients' sense of ~~'~~living with loss~~'~~ when they are re-integrated into their social environment.

6.13 Recommendations for national practice development

The findings of this small scale qualitative study demonstrate the close relationships and interplay between the two health interventions ~~'~~stoma care~~'~~ and ~~'~~HPN treatment~~'~~ in these ~~patients'~~participants' everyday lives. These discoveries could provide resonance to other nutrition support teams who look after patients with a stoma receiving HPN. The researcher intends to share the study findings with the Sheffield ~~local teams for~~ HPN team ~~and~~ in-patient NST. ~~T during regular team meetings. T~~This provides the researcher the opportunity to discuss the implications for changes in professional practice. The researcher also plans to write up this small scale research study and submit for publication in one of the peer reviewed professional journals. The implications for national practice will now be discussed.

The current NHS England standard contract for the provision of intestinal failure (adult) service specified the availability of a range of inter-dependent

services to patients with intestinal failure receiving HPN. One of these services was clinical psychology / psychiatry, which was provided by the two UK national intestinal failure centres based at St Marks Hospital, London and Royal Salford Hospital (formerly Hope Hospital). The findings from this study suggested that a very small number of patients with a stoma receiving HPN continued to experience a deep sense of living with loss. Appropriate patients should have access to specialist services despite the positive general health changes associated with HPN treatment.

Nutrition support teams ~~from other hospitals~~ could enquire about their patients' social wellbeing before discharge from hospital and when they attended out-patient clinics. In addition to the HPN out-patient clinic appointment which was usually held at six to eight weeks after hospital discharge, the patients' GP or practice nurse could provide interim reviews or visits of these patients when they came to collect repeat FP 10 prescriptions. These opportunities for patient contact might flag up early signs of problems with social wellbeing, which would not be detected from weight measurements or blood test~~s~~ results at the HPN clinic. Early detection of problems with social wellbeing by the GP could lead to the offer of prompt remedial support and therapy to these patients, who struggled with the life changes imposed upon them by ~~the~~ stoma care and HPN treatment.

6.14 Implications for future research

The theory generated from the findings of this study is supported by existing published literature on stoma care and those on HPN treatment. The discovery of the close connections between stoma care and HPN treatment in this current study has highlighted opportunities for further research and these will be discussed in the following sections.

The publication of the instrument, HPN-QoL, developed by Baxter et al. (2010) was intended to measure the QoL of patients receiving HPN. (HPN-QoL) (Baxter et al., 2010). This HPN-specific instrument had been extensively validated using data collected from patients with intestinal failure receiving HPN. This 49-item questionnaire assessed the patients' experience with HPN but there were only two items on stoma. The findings from this study suggest that patients with a stoma receiving HPN experienced a sense of 'living with loss' when making adaptations and adjustments in daily activities and social interactions. Therefore, these two items on stoma in the HPN-QoL questionnaire were insufficient in providing meaningful information about the impact of stoma care on the patients' overall QoL living with HPN.

The findings from this grounded theory study supported the need for implied that future quantitative research studies which assessed the QoL of patients with a stoma receiving HPN toshould include items for both stoma care and HPN treatment. This current study has demonstrated that these two health interventions have close connections in the extent of the impact and influences they had on the patients' daily lives and their overall quality of life.

There is a paucity of information about the impact of psychological support available to patients with a stoma receiving HPN in the UK. At a local level the Sheffield Clinical Commissioning Group is responsible for the funding of HPN treatment. The researcher is planning to share the findings and recommendations from this small scale research study with the Sheffield CCG. This provides the researcher the opportunity to highlight the need for the commissioner to consider the availability and accessibility of psychological support to patients with a stoma receiving HPN. Future qualitative research studies might be considered in order to generate

knowledge about the impact of HPN ~~this health intervention~~ on these patients' social wellbeing.

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References

Aronovitch, S. A., Sharp, R. and Harduar-Morano, L. (2010) Quality of life for patients living with ostomies influence of contact with an ostomy nurse. *Journal of Wound Ostomy and Continence Nursing,* 37 (6)**,** pp. 649-653.

Barbour, R. S. (2001) Checklists for improving rigor in qualitative research: a case of the tail wagging the dog? *British Medical Journal,* 322 (7294)**,** pp. 1115-1117.

Barsoum, N. and Kleeman, C. (2002) Now and then, the history of parenteral fluid administration. *American Journal of Nephrology,* 22 (2-3)**,** pp. 284-289.

Baxter, J. P., Fayers, P. M. and McKinlay, A. W. (2005) A review of the instruments used to assess the quality of life of adult patients with chronic intestinal failure receiving parenteral nutrition at home. *British Journal of Nutrition,* 94 (5)**,** pp. 633-638.

Baxter, J. P., Fayers, P. M. and McKinlay, A. W. (2010) The clinical and psychometric validation of a questionnaire to assess the quality of life of adult patients treated with long-term parenteral nutrition. *Journal of Parenteral and Enteral Nutrition,* 34 (2)**,** pp. 131-142.

Benson, J. and Britten, N. (2006) What effects do patients feel from their antihypertensive tablets and how do they react to them? Qualitative analysis of interviews with patients. *Family Practice*, 23 (1), pp. 80-87.

Bergner, M., Bobbitt, R. A., Carter, W. B. and Gilson, B. S. (1981) The Sickness Impact Profile: development and final revision of a health status measure. *Medical Care,* 19 (8)**,** pp. 787-805.

Berry, J. G., Goldmann, D. A., Mandl, K. D., Putney, H., Helm, D., O'Brien, J., Antonelli, R. and Weinick, R. M. (2011) Health information management and perceptions of the quality of care for children with tracheotomy: A qualitative study. *BMC Health Services Research*, 11, p.117.

Britten, N., Jones, R., Murphy, E. and Stacy, R. (1995) Qualitative research methods in general-practice and primary-care. *Family Practice*, 12 (1), pp. 104-114.

Byrne, W. J., Ament, M. E., Burke, M. and Fonkalsrud, E. (1979) Home parenteral nutrition. *Surgery, gynecology & obstetrics,* 149 (4)**,** pp. 593-99.

Calman, K. C. (1984) Quality of life in cancer patients: an hypothesis. *Journal of Medical Ethics,* 10 (3)**,** pp. 124-127.

Carlson, G. L., Maguire, G., Williams, N., Bradley, A., Shaffer, J. L. and Irving, M. H. (1995) Quality of life on home parenteral nutrition - a single-center study of 37 patients. *Clinical Nutrition,* 14 (4)**,** pp. 219-228.

Carlson, G. L. (2003) Surgical management of intestinal failure. *Proceedings of the Nutrition Society,* 62 (3)**,** pp. 711-718.

Carlsson, E., Berglund, B. and Nordgren, S. (2001) Living with an ostomy and short bowel syndrome: practical aspects and impact on daily life. *Journal of wound, ostomy, and continence nursing* 28 (2), pp. 96-105.

Carlsson, E., Bosaeus, I. and Nordgren, S. (2003) Quality of life and concerns in patients with short bowel syndrome. *Clinical Nutrition*, 22 (5), pp. 445-452.

Carter, D. M., Wheatley, C., Payne-James, J. J. and Pick, A. (1993) Home nutrition survey in the UK: The patient's perspective. *Clinical Nutrition,* 12 (4)**,** pp. 208-212.

Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis.* London: Sage.

Corbin, J. and Strauss, A. (2008) *Basics of qualitative research: techniques and procedures for developing grounded theory.* Thousand Oaks, CA: Sage.

Cornwell, J. and Robert, G. (2011) *Designing the future: approaches to measuring patient experience.* Kings Fund. Available from:

http://www.kingsfund.org.uk/publications/articles/designing-future-approaches-measuring-patient-experience (Accessed 14 May 2014).

Craig, R., Neumann, T., Yokoo, H. and Jeejeebhoy, K. (1978) Alcoholic-like liver disease with severe short bowel syndrome maintained on home parenteral nutrition. *Gastroenterology,* 74 (5)**,** p.1022.

Creswell, J. W. (2009) *Research design: qualitative, quantitative, and mixed methods approaches*. 3rd ed. London: Sage.

Creswell, J. W. (2013) *Qualitative inquiry & research design: choosing among five approaches*. 3rd ed. London: Sage.

Cronin, P., Ryan, F. and Coughlan, M. (2008) Undertaking a literature review: a step-by-step approach. *British journal of nursing (Mark Allen Publishing),* 17 (1)**,** pp. 38-43.

Cuthbertson, D. P. and Stewart, C. P. (1945) Protein metabolism. *British medical journal,* 2**,** p. 815.

Denscombe, M. (2003) *The good research guide: for small-scale social research projects.* 2nd ed. Maidenhead: Open University Press.

Denzin, N. K. and Lincoln, Y. S. (1998) *The landscape of qualitative research: theories and issues.* (Handbook of qualitative research) Thousand Oaks, Calif.; London: Sage Publications.

Department of Health (2008) *High quality care for all NHS next stage review final report.* London: Department of Health

Detsky, A. S., McLaughlin, J. R., Abrams, H. B., Labbe, K. A., Whitwell, J., Bombardier, C. and Jeejeebhoy, K. N. (1986) Quality-of-life of patients on long-term total parenteral-nutrition at home. *Journal of General Internal Medicine,* 1 (1)**,** pp. 26-33.

DiCicco-Bloom, B. and Crabtree, B. F. (2006) The qualitative research interview. *Medical Education*, 40 (4), pp. 314-321.

Draper, A. K. (2004) The principles and application of qualitative research. *The Proceedings of the Nutrition Society*, 63 (4), pp. 641-646.

Dudrick, S. J., Wilmore, D. W., Vars, H. M. and Rhoads, J. E. (1968) Long-term total parenteral nutrition with growth, development, and positive nitrogen balance. *Surgery,* 64 (1)**,** pp. 134-142

Dudrick, S. J., Wilmore, D. W., Vars, H. M. and Rhoads, J. E. (1969) Can intravenous feeding as sole means of nutrition support growth in child and restore weight loss in an adult - an affirmative answer. *Annals of Surgery,* 169 (6)**,** pp. 974-984.

Dudrick, S. J. and Rhoads, J. E. (1971) New horizons for intravenous feeding. *Journal of the American Medical Association,* 215 (6)**,** pp. 939-949.

Dudrick, S. J., Odonnell, J. J., Englert, D. M., Matheny, R. G., Blume, E. R., Nutt, R. E., Hickey, M. S. and Barroso, A. O. (1984) 100 patient-years of ambulatory home total parenteral-nutrition. *Annals of Surgery,* 199 (6)**,** pp. 770-781.

Dudrick, S. J. (2003) Early developments and clinical applications of total parenteral nutrition. *Journal of Parenteral and Enteral Nutrition,* 27 (4)**,** pp. 291-299.

Dudrick, S. J. (2009) History of Parenteral Nutrition. *Journal of the American College of Nutrition,* 28 (3)**,** pp. 243-251.

Elia, M. (1995) An international perspective on artificial nutritional support in the community. *The Lancet,* 345 (8961)**,** pp. 1345-1349.

Elia, M., Stratton, R. J., Holden, C., Meadows, N., Micklewright, A., Russell, C., Scott, D., Thomas, A., Shaffer, J., Wheatley, C. and Woods, S. (2001) Home artificial nutritional support: the value of the British Artificial Nutrition Survey. *Clinical Nutrition,* 20**,** pp. 61-66.

Elman, R. (1937) Amino-acid content of the blood following intravenous injection of hydrolyzed casein. *Proceedings of the Society for Experimental Biology and Medicine,* 37 (3)**,** pp. 437-440.

Emedo, M.-J., Godfrey, E. I. and Hill, S. M. (2010) A Qualitative Study of the Quality of Life of Children Receiving Intravenous Nutrition at Home. *Journal of Pediatric Gastroenterology and Nutrition*, 50 (4), pp. 431-440.

Faulk, D. L., Anuras, S. and Freeman, J. B. (1978) Idiopathic chronic intestinal-pseudo-obstruction - use of central venous nutrition. *Journal of the American Medical Association,* 240 (19)**,** pp. 2075-2076.

Fielding, N. G. and Fielding, J. L. (1986) *Linking data.* (Qualitative research methods series) Beverly Hills; London: Sage.

Fitzpatrick, R. and Boulton, M. (1994) Qualitative methods for assessing health care. *Quality in health care: QHC*, 3 (2), pp. 107-113.

Fleming, C. R., Beart, R. W., Berkner, S., McGill, D. B. and Gaffron, R. (1980) Home parenteral-nutrition for management of the severely malnourished adult patient. *Gastroenterology,* 1979 (1)**,** pp. 11-18.

Floruta, C. V. (2001) Dietary choices of people with ostomies. *Journal of WOCN,* 28 (1)**,** pp. 28-31.

Fortune, D. G., Varden, J., Parker, S., Harper, L., Richards, H. L. and Shaffer, J. L. (2005) Illness beliefs of patients on home parenteral nutrition (HPN) and their relation to emotional distress. *Clinical Nutrition,* 24 (6)**,** pp. 896-903.

Gardner, K. and Chapple, A. (1999) Barriers to referral in patients with angina: qualitative study. *British Medical Journal*, 319 (7207), pp. 418-421.

Glaser, B. G. (1978) *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: Sociology Press.

Glaser, B. G. and Strauss, A. L. (1967) *The discovery of grounded theory : strategies for qualitative research.* New York: Aldine de Gruyter.

Greenhalgh, T. and Taylor, R. (1997) How to read a paper - Papers that go beyond numbers (qualitative research). *British Medical Journal,* 315 (7110)**,** pp. 740-743.

Greig, P. D., Jeejeebhoy, K. N., Langer, B. and Cohen, Z. (1981) A decade of home parenteral nutrition. *Gastroenterology,* 80 (5)**,** pp. 1164-1164.

Harrison, R. J. and Booth, C. C. (1960) Massive resection of the small intestine after occlusion of the superior mesenteric artery. *Gut,* 1**,** pp. 237-241.

Henriques, V. and Andersen, A.C. (1913) Uber parenterale Ernahrung durch intravenose injection. *Zeit Physiol Chem,* 88, pp. 357–678.

Herfindal, E. T., Bernstein, L. R., Kudzia, K. and Wong, A. (1989) Survey of home nutritional support patients. *Journal of Parenteral and Enteral Nutrition,* 13 (3)**,** pp. 255-261.

Holloway, I. and Walker, J. (1999) *Getting a PhD in health and social care.* Oxford; Malden, MA, USA: Blackwell Science.

Howard, L., Ament, M., Fleming, C. R., Shike, M. and Steiger, E. (1995) Current use and clinical outcome of home parenteral and enteral nutrition therapies in the united-states. *Gastroenterology,* 109 (2)**,** pp. 355-365

Howard, L., Heaphey, L., Fleming, C. R., Lininger, L. and Steiger, E. (1991) 4 years of North-American registry home parenteral-nutrition outcome data and their implications for patient-management. *Journal of Parenteral and Enteral Nutrition,* 15 (4)**,** pp. 384-393.

Huisman-de Waal, G., Naber, T., Schoonhoven, L., Persoon, A., Sauerwein, H. and van Achterberg, T. (2006) Problems experienced by patients receiving

parenteral nutrition at home: results of an open interview study. *Journal of Parenteral and Enteral Nutrition,* 30 (3)**,** pp. 215-221.

Jeejeebhoy, K. N., Langer, B., Tsallas, G., Chu, R. C., Kuksis, A. and Anderson, G. H. (1976) Total parenteral nutrition at home - studies in patients surviving 4 months to 5 years. *Gastroenterology,* 71 (6)**,** pp. 943-953.

Jeppesen, P. B., Langholz, E. and Mortensen, P. B. (1999) Quality of life in patients receiving home parenteral nutrition. *Gut,* 44 (6)**,** pp. 844-852.

Johansson, C., Ekelund, K. and Rubios, C. (1976) Jejunitis with malabsorption - quantitative study of gastric and intestinal handling of a meal during malabsorption and after recovery. *Scandinavian Journal of Gastroenterology,* 11 (7) pp. 729-734.

Johnston, O., Kumar, S., Kendall, K., Peveler, R., Gabbay, J. and Kendrick, T. (2007) Qualitative study of depression management in primary care: GP and patient goals, and the value of listening. *British Journal of General Practice*, 57 (544), pp. 872-879.

Jones, B. J. M. (2003) Recent developments in the delivery of home parenteral nutrition in the UK. *Proceedings of the Nutrition Society,* 62 (3)**,** pp. 719-725.

Keats, D. M. (2000) *Interviewing: a practical guide for students and professionals*. Buckingham: Open University Press.

Kneck, A., Klang, B. and Fagerberg, I. (2011) Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus. *Scandinavian Journal of Caring Sciences*, 25 (3), pp.558-566.

Knowles, S. R., Cook, S. I. and Tribbick, D. (2013) Relationship between health status, illness perceptions, coping strategies and psychological morbidity: A preliminary study with IBD stoma patients. *Journal of Crohn's and Colitis,* 7 (10)**,** pp.471-478.

Kubler-Ross, E. (1970) *On death and dying.* London: Tavistock/Routledge.

Kuper, A., Reeves, S. and Levinson, W. (2008) Qualitative research - An introduction to reading and appraising qualitative research. *British Medical Journal*, 337: a288.

Kuziemsky, C. E., Downing, G. M., Black, F. M. and Lau, F. (2007) A grounded theory guided approach to palliative care systems design. *International journal of medical informatics*, 76 Suppl 1, pp.41-48.

Kvale, S. (1996) *Interviews: an introduction to qualitative research interviewing*. Thousand Oaks; London: Sage.

Kvale, S. (2007) *Doing interviews*. (Sage qualitative research kit) London: Sage Publications.

Ladefoged, K. (1981) Quality of life in patients on permanent home parenteral-nutrition. *Journal of Parenteral and Enteral Nutrition,* 5 (2)**,** pp. 132-137.

Lennard-Jones, J. (1992) *A Positive Approach to Nutrition as Treatment.* Kings Fund Centre: Available from: http://www.bapen.org.uk/pdfs/bapen_pubs/pub_kings_fund.pdf (Accessed 11 October 2012).

Macht, S. D. (1980) 300 years of parenteral-nutrition - history of intravenous nutritional therapy. *Connecticut Medicine,* 44 (1)**,** pp. 27-30.

Malone, M. (1989) Home parenteral nutrition: Effect of patients' lifestyle. *Clinical Nutrition,* 8 (1)**,** pp. 11-13.

Manderson, L. (2005) Boundary breaches: the body, sex and sexuality after stoma surgery. *Social Science & Medicine,* 61 (2)**,** pp. 405-415.

Marshall, C. and Rossman, G. B. (1999) *Designing qualitative research*. 3rd ed. Thousand Oaks, Calif.; London: Sage.

Mays, N. and Pope, C. (2000) Qualitative research in health care - Assessing quality in qualitative research. *British Medical Journal,* 320 (7226)**,** pp. 50-52.

Mughal, M. and Irving, M. (1986) Home parenteral nutrition in the United Kingdom and Ireland. *Lancet,* 2 (8503)**,** pp. 383-386.

Munday, D., Petrova, M. and Dale, J. (2009) Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England. *British Medical Journal*, 339: b2391.

NHS Choices (2014) *Ileostomy.* NHS Choices. Available from: http://www.nhs.uk/conditions/Ileostomy/Pages/Introduction.aspx (Accessed 01/09/2014).

NHS National Commissioning Group for Highly Specialised Services (2008) *A strategic framework for intestinal failure and home parenteral nutrition services for adults in England.* London: NHS National Commissioning Group for Highly Specialised Services. Available from: http://www.specialisedservices.nhs.uk/library/28/Strategic_Framework_for_Intestinal_Failure_and_Home_Parenteral_Nutrition_Services_for_Adults_in_England_1.pdf (Accessed 13 March 2014).

NICE (2012) *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE clinical guideline 138.* London: NICE. Available from: http://www.nice.org.uk/nicemedia/live/13668/58283/58283.pdf (Accessed 18 February 2014).

Nightingale, J. M. D. (2001) Management of patients with a short bowel. *World Journal of Gastroenterology,* 7 (6)**,** pp. 741-751.

Notter, J. and Burnard, P. (2006) Preparing for loop ileostomy surgery: Women's accounts from a qualitative study. *International Journal of Nursing Studies*, 43 (2), pp. 147-159.

Oliver, P. (2004) *The student's guide to research ethics*. Maidenhead: Open University Press.

Orbach, C. E. and Tallent, N. (1965) Modification of perceived body and body concepts. *Archives of general psychiatry,* 12**,** pp. 126-135.

Orrevall, Y., Tishelman, C. and Permert, J. (2005) Home parenteral nutrition: A qualitative interview study of the experiences of advanced cancer patients and their families. *Clinical Nutrition,* 24 (6)**,** pp. 961-970.

Perl, M., Peterson, L. G., Dudrick, S. J. and Benson, D. M. (1981) Psychiatric effects of long-term home hyperalimentation. *Psychosomatics,* 22 (12)**,** pp. 1047-1063.

Persoon, A., Huisman-de Waal, G., Naber, T. A., Schoonhoven, L., Tas, T., Sauerwein, H. and van Achterberg, T. (2005) Impact of long-term HPN on daily life in adults. *Clinical Nutrition,* 24 (2)**,** pp. 304-313.

Persson, E. and Hellstrom, A.L. (2002) Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *Journal of wound, ostomy, and continence nursing: official publication of The Wound, Ostomy and Continence Nurses Society / WOCN,* 29 (2)**,** pp. 103-108.

Pironi, L., Paganelli, F., Mosconi, P., Morselli-Labate, A. M., Spinucci, G., Merli, C., Guidetti, M. and Miglioli, M. (2004) The SF-36 instrument for the follow-up of health-related quality-of-life assessment of patients undergoing home parenteral nutrition for benign disease. *Transplantation Proceedings,* 36 (2)**,** pp. 255-258.

Pope, C. and Mays, N. (1995) Reaching the parts other methods cannot reach - an introduction to qualitative methodes in health and health-services research. *British Medical Journal*, 311 (6996), pp. 42-45.

Pope, C., van Royen, P. and Baker, R. (2002) Qualitative methods in research on healthcare quality. *Quality & Safety in Health Care*, 11 (2), pp. 148-152.

Popek, S., Grant, M., Gemmill, R., Wendel, C. S., Mohler, M. J., Rawl, S. M., Baldwin, C. M., Ko, C. Y., Schmidt, C. M. and Krouse, R. S. (2010) Overcoming challenges: life with an ostomy. *The American Journal of Surgery,* 200 (5)**,** pp. 640-645.

Price, B. S. and Levine, E. L. (1979) Permanent total parenteral nutrition: psychological and social responses of the early stages. *Journal of parenteral and enteral nutrition,* 3 (2)**,** pp. 48-52.

Puntis, J. W. L. (1998) The economics of home parenteral nutrition. *Nutrition,* 14 (10), pp. 809-812.

Rault, R. M. J. and Scribner, B. H. (1977) Treatment of Crohn's disease with home parenteral nutrition. *Gastroenterology,* 72 (6)**,** pp. 1249-1252.

Reddy, P. and Malone, M. (1998) Cost and outcome analysis of home parenteral and enteral nutrition. *Journal of Parenteral and Enteral Nutrition,* 22 (5)**,** pp. 302-310.

Rhode, C. M., Parkins, W. M. and Vars, H. M. (1949) Nitrogen balances of dogs continuously infused with 50-percent glucose and protein preparations. *American Journal of Physiology,* 159 (3)**,** pp. 415-425.

Richards, D. M. and Irving, M. H. (1996) Cost-utility analysis of home parenteral nutrition. *British Journal of Surgery,* 83 (9)**,** pp. 1226-1229.

Richards, D. M., Scott, N. A., Shaffer, J. L. and Irving, M. (1997) Opiate and sedative dependence predicts a poor outcome for patients receiving home parenteral nutrition. *Journal of Parenteral and Enteral Nutrition,* 21 (6)**,** pp. 336-338.

Richards, D. M., Deeks, J. J., Sheldon, T. A. and Shaffer, J. L. (1997) Home parenteral nutrition: a systematic review. *Health technology assessment (Winchester, England),* 1 (1)**,** pp. i-iii, 1-59.

Schuberth, O. and Wretlind, A. (1963) Fat emulsions for intravenous nutrition. Pharmacological and clinical experiences. *Nordisk medicin,* 69**,** pp. 13-17.

Scolapio, J. S. (2002) Short bowel syndrome. *Journal of Parenteral and Enteral Nutrition,* 26 (5)**,** pp. S11-S16.

Scribner, B. H., Cole, J. J., Christop.Tg, Vizzo, J. E., Atkins, R. C. and Blagg, C. R. (1970) Long-term total parenteral nutrition - concept of an artificial gut. *Journal of the American Medical Association,* 212 (3)**,** pp. 457-463.

Serlick, S. E., Dudrick, S. J. and Flack, H. L. (1969) Nutritional intravenous feeding. *Bulletin of the Parenteral Drug Association,* 23 (4)**,** pp. 166-173.

Sharpe, L., Patel, D. and Clarke, S. (2011) The relationship between body image disturbance and distress in colorectal cancer patients with and without stomas. *Journal of Psychosomatic Research,* 70 (5)**,** pp. 395-402.

Silver, H. J. (2004) The lived experience of home total parenteral nutrition: an online qualitative inquiry with adults, children, and mothers. *Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition,* 19 (3)**,** pp. 297-304.

Silverman, D. (2011) *Interpreting qualitative data: a guide to the principles of qualitative research*. 4th ed. London: Sage.

Smith, C. E. (1993) Quality of life in long-term total parenteral nutrition patients and their family caregivers. *Journal of parenteral and enteral nutrition,* 17 (6)**,** pp. 501-506.

Smith, T. (2011) Adult home parenteral nutrition. In: Smith, T. (ed.) *Annual BANS report 2011: Artificial nutrition support in the UK 2000-2010.* Redditch: BAPEN, pp. 27-36.

Spencer, L., Ritchie, J., Lewis, J. and Dillon, L. (2003) *Quality in qualitative evaluation: A framework for assessing research evidence.* London: Cabinet Office. Available from: http://www.civilservice.gov.uk/wp-

content/uploads/2011/09/Quality-in-qualitative-evaulation_tcm6-38739.pdf (Accessed 24 September 2014).

Stern, P. N. (1994) *Critical issues in qualitative research methods (pp.212-223).* (Eroding grounded theory. In J. M. Morse (Ed) Thousand Oaks, CA: Sage.

Studley, H. O. (2001) Percentage of weight loss: a basic indicator of surgical risk in patients with chronic peptic ulcer. 1936. *Nutricion hospitalaria,* 16 (4)**,** pp. 141-3; discussion 140-141.

Strauss, A. L. (1987) *Qualitative analysis for social scientists.* Cambridge: Cambridge University Press.

Strauss, A. L. and Corbin, J. M. (1990) *Basics of qualitative research: grounded theory procedures and techniques.* Newbury Park; London: Sage.

Strauss, A. L. and Corbin, J. M. (1998) *Basics of qualitative research: techniques and procedures for developing grounded theory.* 2nd ed*.* Thousand Oaks, Calif.; London: Sage Publications.

The Health Foundation (2013) *Measuring patient experience: evidence scan number 18*. London: The Health Foundation. Available from: http://www.health.org.uk/public/cms/75/76/313/4300/Measuring%20patient%20experience.pdf?realName=XbvcWY.pdf (Accessed 18 May 2014).

Van Gossum, A., Bakker, H., DeFrancesco, A., Ladefoged, K., LeonSanz, M., Messing, B., Pironi, L., Pertkiewicz, M., Shaffer, J., Thul, P. and Wood, S. (1996) Home parenteral nutrition in adults: A multicentre survey in Europe in 1993. *Clinical Nutrition,* 15 (2)**,** pp. 53-59.

Vinnars, E. and Wilmore, D. (2003) History of parenteral nutrition. *Journal of Parenteral and Enteral Nutrition,* 27 (3)**,** pp. 225-231.

Wanten, G., Calder, P. C. and Forbes, A. (2011) Managing adult patients who need home parenteral nutrition. *British Medical Journal,* 342, d1447.

Wateska, L. P., Sattler, L. L. and Steiger, E. (1980) Cost of a home parenteral nutrition program. *Journal of the American Medical Association,* 244 (20)**,** pp. 2303-2304.

WHO (1997) *WHOQOL: Measuring quality of life.* Geneva: WHO. Available from: *www.who.int/mental_health/media/68.pdf* (Accessed 28 February 2014).

Winkler, M. F. (2005) Quality of life in adult home parenteral nutrition patients. *Journal of Parenteral and Enteral Nutrition,* 29 (3)**,** pp. 162-170.

Winkler, M. F., Hagan, E., Wetle, T., Smith, C., Maillet, J. O. and Touger-Decker, R. (2010) An Exploration of Quality of Life and the Experience of Living With Home Parenteral Nutrition. *Journal of Parenteral and Enteral Nutrition,* 34 (4)**,** pp. 395-407.

Wong, C., Lucas, B. and Wood, D. (2014) Patients' experiences with home parenteral nutrition: a literature review. *European Journal of Hospital Pharmacy*, 22 (1), pp. 51-55.

Wretlind, A. (1992) Recollections of pioneers in nutrition - landmarks in the development of parenteral-nutrition. *Journal of the American College of Nutrition,* 11 (4)**,** pp. 366-373.

Appendix 1 European Journal of Hospital Pharmacy

Patients' experiences with home parenteral nutrition: a literature review

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ABSTRACT

Aim The aim of this review is to summarise the literature relating to patients' experiences with home parenteral nutrition (HPN).

Method This literature review is based on searches of CINAHL, PubMed, Web of Knowledge and Web of Science for articles published between 1970 and 2013. Additional studies were included from Department of Health publications, NICE clinical guidance, UK patient support group with interests in HPN or intestinal failure (IF).

Results Patients with severe IF have been successfully treated with HPN since the 1970s. Early published studies evaluated clinical outcomes such as catheter-related infections, metabolic complications, thrombosis of the catheterised vein and liver impairment. Since the 1980s questionnaire studies were used to evaluate the quality of life (QoL) of patients treated with HPN. These early studies used QoL assessment tools which were not validated for patients treated with HPN. Internationally, there were published qualitative research studies which explored the experiences of patients treated with HPN.

Conclusions The long-term outcome of patients treated with HPN continues to attract research interest. The review of the literature did not identify any published qualitative studies on the experiences of patients treated with HPN in the UK, suggesting a gap in the research. The UK National Health Service advocates a patient-centred approach for service design and delivery in primary and secondary care. This literature review has highlighted opportunities for qualitative research into the experiences of patients living with HPN to achieve better understanding and awareness of the rehabilitation of these patients.

INTRODUCTION

Parenteral nutrition (PN) is an admixture consisting of sterile and nutritionally balanced macronutrients and micronutrients for intravenous administration.[1] This form of artificial nutrition can save lives in patients who have intestinal failure (IF).[2] IF is a condition associated with extensive loss of absorptive function and capacity of the small intestines.[3] There are many different causes ranging from obstruction,[4] abnormal motility, major surgical resection, congenital defects and severe inflammatory bowel disease.[5] The main problem in IF is the failure of the small bowel to absorb nutrients (fat, protein and carbohydrate), water, minerals and vitamins from the diet to maintain health or sustain life.[6]

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Parenteral nutrition

Patients with IF develop a range of health problems and the term 'short bowel syndrome' (SBS) is used to describe the clinical consequences caused by IF.[7] Before the discovery of PN in the 1960s patients would die from starvation caused by chronic malnutrition.[6] During the 1970s and 1980s clinicians in the USA started to provide parenteral nutrition at home to adults who suffered chronic IF due to non-malignant diseases.[8] Home parenteral nutrition (HPN) involves the delivery and administration of a sterile admixture containing optimally balanced macronutrients, micronutrients and electrolytes in a single infusion bag at the patient's home. The patient has a long-term indwelling central venous catheter for administration of the feed admixture. Patients or their main carers have to learn the skills and aseptic techniques needed to set up the infusion and to connect to the catheter at home overnight. In some cases patients receive help from specialist nurses, who look after the central venous catheter and carry out the connection and disconnection of the HPN feed. Once they are clinically and metabolically stable with the infusion during hospital stay, they continue with HPN following discharge. Patients receiving HPN can continue oral diet and fluids but they need to follow a low residue diet advised by dieticians and take oral medications to reduce losses from ileostomies or chronic severe diarrhoea.[9] Patients with severe chronic malnutrition become dependent on lifelong treatments. They live with these healthcare interventions in the same way as those with chronic conditions.

Demand for HPN

In the UK the first patient was discharged home on HPN from St Marks Hospital, London in 1976 and from Salford Royal Hospital (formerly Hope Hospital) in 1978.[10] Over the years many patients were offered this ambulatory treatment and HPN is now widely used in Western countries.[11 12] The North American HPN Patient Registry reported a prevalence of 120 per million population for HPN between 1989 and 1992.[11] In 1993 a European retrospective survey from 13 countries and 75 centres, involving adult patients with non-malignant primary disease receiving HPN reported an incidence of 0.2–4.6 and a prevalence of 0.3–12.2 patients per million population per year.[13] In 1997 a UK health technology assessment identified differences between countries in the underlying diseases for which HPN is indicated. It reported that HPN was offered to more patients with an underlying malignancy in Italy and the USA than in the UK (40–70% vs 8%).[14] In 2008 the UK National Commissioning Group reported that 18 adult patients per million population require prolonged management of IF in hospitals,

and 14.6 adult patients per million population need HPN on discharge from hospital.[15]

In 2011 the British Artificial Nutrition Survey (BANS)[16] published data collected from 2000 to 2010. The reported UK HPN point prevalence was 8.40 per million population during 2010. This survey also found that SBS was the most common reason for HPN (54.4% new cases; 58.9% established cases). Crohn's disease, small bowel ischaemia and pseudo-obstruction were the major indications for new HPN cases (18.4%, 9.7% and 11% respectively) and established cases (29.3%, 15.3% and 15.1%).

In 2010 there were 228 new adult patients registered for HPN, compared with 148 in 2009 and 157 in 2008, representing a rise in clinical demand in the UK.[16] In contrast, 3430 adults were newly registered for home enteral tube feeding in 2010.[16] The number of newly registered adult patients receiving HPN was low in comparison to other common chronic conditions, such as hypertension and diabetes. Therefore, only a very small number of GPs are likely to come across a patient treated with HPN in their practices.

Patients living with HPN

The latest BANS report[16] also explored the HPN patients' 'ability to manage' and their 'activity level'. It found that 60.1% and 71% of newly registered adult patients were described as 'independent' and 'fully independent' respectively for 'ability to manage' following discharge from hospitals. For 'activity level' it found that only 68% of patients were described as 'fully active', whilst nearly 40% required 'some help' or 'total help' at home. From this latter group, 'limited activity' was reported by 28.5%, with 3.5% and 2.5% remaining house bound or bed bound respectively. The report did not give details on what help was needed by these patients, or who provided the help. All the data were submitted by healthcare professionals of the nutrition support teams (NSTs) from 21 HPN centres. They assessed the patients and then directly submitted the data onto collection forms. The data represented limited insight into the patients' experiences with HPN.

Patients' experiences with the National Health Service

In 2008 Lord Darzi's report 'High quality care for all'[17] highlighted the importance of the entire patient experience within the National Health Service (NHS). In 2012 the National Institute for Health and Care Excellence (NICE) provided the NHS with clear guidance on the components of a good patient experience. It emphasised the need for service providers to ensure services are designed in a way that they respond to the needs, preferences and values of the patient. It recommended that service providers should encourage the patients to give feedback about their care, and the providers should respond to any feedback given.[18]

Patient representation on the HPN framework committee provides a valuable contribution to the design and commissioning of HPN services across the UK. The availability of published qualitative data on patients' experiences with HPN could support the Clinical Commissioning Groups when making decisions on the provision and improvement of IF and HPN services for adults in England. The aim of this review is to provide an account of patients' experiences with HPN following discharge from hospital.

METHODS

Search strategy

CINAHL, PubMed, Web of Science and Web of Knowledge were searched for relevant articles published between 1970 and 2013. All included studies have been published in the English language. Additional studies were included from reference lists of eligible papers, including Department of Health publications, NICE clinical guidance, UK charities, and patient support/self-help groups with interests in HPN or IF, and NHS England publications.

Inclusion criteria

Qualitative studies that assessed or evaluated HPN and adults' experiences with PN at home respectively were included. Eligible patients were those who could eat and drink but were also partially or fully dependent on HPN (with or without additional intravenous fluids, with or without antimotility drugs) for chronic malabsorption and malnutrition problems, and lived in the community (privately or in residential/nursing homes). All causes of IF in patients with non-malignancy were included.

Exclusion criteria

Studies which examined the clinical issues of HPN, involved children as participants, and those published in a language other than English.

Search terms

HPN, IF, patient experiences, adults, quality of life.

RESULTS

The results are now presented as thematic areas identified within the literature.

Mortality of HPN

During the 1970s and 1980s the clinical outcomes of HPN were studied by many researchers in the UK, the USA and European countries. They reported on the prevention of certain death,[19] reduction in hospital stay,[20] remission of bowel obstruction due to Crohn's disease, weight gain and improved biochemical profiles.[21–23] The focus was on keeping these patients alive and monitoring for side effects of treatment, such as catheter-related infection episodes[8] and liver abnormalities.[24]

Living a life with HPN

One study used a qualitative methodology to observe 19 patients treated with HPN at home. The researchers found that these patients experienced psychological problems of anger, anxiety, depression, loss of ability to eat, negative body image and relationship problems.[25] Another study which observed 10 patients receiving HPN over 2 years reported similar findings of depression, fear, anxiety, body image distortion, marital stress and sexual difficulties.[26] These discoveries led to changes in the research paradigm with subsequent investigations into the impact of HPN on patients' quality of life (QoL).

QoL indicators

WHO defines QoL as:

> an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social

relationships, personal benefits and their relationship to salient features of their environment.[27]

Away from the healthcare setting, Calman[28] believes that 'the quality of life can only be described and measured in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions'. He advocates that 'quality of life must include all areas of life and experience and take into account the impact of illness and treatment'.

In 1989 a written questionnaire survey carried out by a major US home care company reported that half of the 347 patients receiving HPN were less satisfied with life as a whole in comparison to the overall US population and to those with end-stage renal disease.[29] Carlsson et al[30] studied patients with IF due to SBS and they found that patients who were dependent on HPN rated a lower QoL than those without HPN. The authors echoed Calman's statement in their discussion and concluded that when asking a subject to rate personal QoL we must appreciate what this concept means to him/her.

Most studies with patients receiving HPN used generic quantitative assessment tools to evaluate QoL. Ladefoged[31] used a simple ordinal scale of 'poor, fair or good' to measure QoL. Detsky et al[32] measured the QoL in terms of quality-adjusted survival. Others used existing generic or disease-specific sickness impact profile (SIP),[33] the inflammatory bowel disease questionnaire[34] or the short form health survey (SF-36).[30 35] All these studies assessed participants against descriptive criteria chosen by the researchers. In other words the researchers made decisions on what information they wanted to ascertain from participants.

Persoon et al[36] reported that patients receiving HPN experienced a number of psychosocial problems in everyday life. These ranged from anxiety, lack of freedom to limitations in social life caused by HPN dependence. Richard et al[37] found that some patients receiving HPN, who were already taking opiates and benzodiazepines to control pain and anxiety from their underlying diseases, developed more episodes of catheter-related infection. Other studies found that patients treated with HPN described depression as the most common psychological problem.[38] Female patients receiving HPN often experienced depression and discouragement, and they appeared more tearful and upset than male patients.[34] It is becoming evident that HPN can have a significant negative impact on a patient's life style and QoL.[39]

In 2005 a systematic review published by Baxter et al[40] criticised the three QoL instruments commonly used for measuring health outcomes in patients receiving HPN (see table 1).

SF-36 is disease specific for inflammatory bowel diseases only; the EuroQoL EQ-5D consists of non-validated questionnaires. SIP is the only one which involves patient interviews but it is not HPN specific. Baxter et al were concerned with the lack of standardisation in their use for measuring QoL in health outcomes. They found that patients receiving HPN continued to have symptoms caused by the underlying disease which had resulted in the need for HPN. They concluded that when assessing patients' QoL, it is important to ask questions that are relevant, pertinent and sensitive to issues that are most important to them. Orrevall's[41] quote from a woman, whose husband had recently begun HPN, illustrated the need for health researchers to re-think how we should assess the patients' QoL:

> You can say that it gives quality of life to the rest of the family and to the patient if you can turn a negative spiral around like this ... I can only say that I'm happy about the drip, that he gets such energy and strength, and with that comes pleasure and yes, there's certainly a kind of harmony from it.

This qualitative study discovered that the most positive aspect of HPN was 'a sense of relief and security that nutritional needs were met'. It also found that the most negative effect of HPN was related to the 'restrictions in family life and social contacts'. Both the participants and their family members experienced physical, social and psychological benefits from HPN treatment.

An open interview study in the Netherlands reported that patients receiving HPN experienced negative emotions, physical problems, social limitations, dependence on others, incapability, and patient-care provider problems.[42]

A qualitative telephone interview of patients receiving HPN and their family carers found that both patients and carers experienced loss of friends, loss of employment and depression.[43] Another qualitative study used online semi-structured interviews and it discovered six major themes: affirmation of life, infusion-related complications, lifestyle adaptations, self-worth, isolation, and food intake.[44] This provided insights into the daily lives and experiences of patients treated with HPN.

In 2010 Winkler et al[45] published the findings of a qualitative study which explored the QoL and experiences of living with HPN in adults with IF in the USA. The authors used content and the interpretative phenomenological analysis method and they discovered that these patients viewed HPN as a 'life-line' and 'nutritional safety net'. Participants in this study defined QoL as 'enjoying life', 'being happy, satisfied, or content with life', and 'being able to do what you want to do, when you want to do it'. They described their QoL as 'good' to 'wonderful' and they all wanted 'normality in life'. The authors believed that qualitative research methodology provides new insights and richness of data from patient treated with HPN. In the same year researchers from Scotland published a validated tool, 'HPN-QOL', to assess the QoL of patients receiving HPN.[46] They recommended that this questionnaire should form part of the routine clinical management of patients treated with HPN.

UK experience

In 1989 the Nutrition Unit at Salford Royal Hospital (formerly Hope Hospital) published its findings on the effect of HPN on the lifestyle and employment of 30 patients using a standard

Table 1 Instruments and methods used to measure quality of life in patients on home parenteral nutrition[40]

Generic instruments	Disease-specific instruments	Non-validated instruments
Short Form 36 (SF-36)—assesses functioning in eight domains*	Inflammatory Bowel Disease Questionnaire (IBDQ)	Time trade-off/category scaling and direct questioning
EuroQoL EQ-5D—a single score on a quality of life scale (0 worse to 100 best)	Quality of life inventory	Non-validated questionnaires
Sickness Impact Profile (SIP)	Quality of life index Rotterdam symptom checklist	Patient interviews

*The eight domains are: physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy/vitality, pain and general health perception.

questionnaire designed for the study.[47] These researchers found that patients receiving HPN experienced unemployment, sleep disruption, travel limitations and had reduced satisfaction with social and family lives. In 1993 the first UK HPN patient questionnaire survey was carried out by the organisation 'Patients on Intravenous and Naso-Gastric Nutrition Therapy' (PINNT). This survey collected information from members of PINNT about the service from the patients' perspectives.[48] The survey reported that most patients were happy with the commercial home healthcare companies, and patients who required the shortest feed infusion time experienced minimal interruptions to daily routines at home.

In 2001 the first BANS report published results from annual questionnaires completed by NST from more than 200 UK centres each year between 1996 and 1999.[49] This was the first time that detailed information on patients' experiences with HPN had been collected by NST. They found that 74% of patients had disrupted sleep during overnight feed infusions. Noise was a problem and 21% of patients found that the infusion pump and its alarm were too noisy, while 8% found the refrigerator used to store the feed solutions was too noisy. Seventeen percent of patients disliked the inconvenience of having to keep hospital-style infusion equipment at home. Over 60% of them stated that the drip stand, the infusion pump and the stainless steel trolley took up too much space, restricting mobility within the home. Over the years technological improvements have led to the use of smaller, portable infusion drip stands and pumps. Today HPN equipment occupies mush less space within the home than it did three decades ago.

In 2005 Fortune et al[50] investigated the significance of emotional distress experienced by patients with IF treated with HPN. They reported two predictors for emotional distress: the lack of control over aspects of their underlying condition and treatment, and the perception that the condition and treatment make little sense to them.

CONCLUSIONS

HPN is an established treatment modality for patients with malabsorption and malnutrition from chronic IF. Early studies focused on the clinical outcomes and complications associated with this treatment. This literature review identified a number of published studies which examined the non-clinical outcome of adults living with HPN. Researchers used a range of instruments and methods to assess the psychological and social impact of HPN and their QoL (see table 1). However, these assessment tools, questionnaires, surveys and scales were not validated for patients receiving HPN. Following the publication of a validated tool, 'HPN-QOL', to assess the QoL of patients treated with HPN,[46] we have not come across any published research studies in this patient group using the HPN-QOL questionnaire.

This small-scale review included studies conducted in the UK, the USA and European countries. There are very few published studies of patients' perception of living with this ambulatory treatment in the UK. This provides a strong rationale for further qualitative research studies providing the opportunity for patients receiving HPN to have a voice in such an intervention. The experiences of these patients should be made available to clinical commissioning groups who are responsible for service development in local communities.

Contributors BL and DW provided guidance and advice in the evaluation of published qualitative and quantitative studies respectively, for inclusion in the preparation of this literature review. Both coauthors made substantial contributions to drafting and revising this paper, and its final approval.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1 NICE. Nutrition support in adults. NICE clinical guideline 32. London: NICE; 2006. http://www.nice.org.uk/CG32.
2 Scribner BH, Cole JJ, Christop TG, et al. Long-term total parenteral nutrition: the concept of an artificial gut. JAMA 1970;212:457–63.
3 Johansson C, Ekelund K, Rubios C. Jejunitis with malabsorption. A quantitative study of gastric and intestinal handling of a meal during malabsorption and after recovery. Scand J Gastroenterol 1976;11:729–34.
4 Faulk DL, Anuras S, Freeman JB. Idiopathic chronic intestinal-pseudo-obstruction. Use of central venous nutrition. JAMA 1978;240:2075–76.
5 Carlson GL. Surgical management of intestinal failure. Proc Nutr Soc 2003;62:711–18.
6 Harrison RJ, Booth CC. Massive resection of the small intestine after occlusion of the superior mesenteric artery. Gut 1960;1:237–41.
7 Scolapio JS. Short bowel syndrome. JPEN2002;26:S11–16.
8 Dudrick SJ, Odonnell JJ, Englert DM, et al. 100 patient-years of ambulatory home total parenteral-nutrition. Ann Surg 1984;199:770–81.
9 Nightingale JMD. Management of patients with a short bowel. World J Gastroenterol 2001;7:741–51.
10 Jones BJM. Recent developments in the delivery of home parenteral nutrition in the UK. Proc NutrSoc 2003;62:719–25.
11 Howard L, Ament M, Fleming CR, et al. Current use and clinical outcome of home parenteral and enteral nutrition therapies in the United-States. Gastroenterology 1995;109:355–65.
12 Elia M. An international perspective on artificial nutritional support in the community. Lancet 1995;345:1345–49.
13 Van Gossum A, Bakker H, DeFrancesco A, et al. Home parenteral nutrition in adults: a multicentre survey in Europe in 1993. Clin Nutr 1996;15:53–9.
14 Richards DM, Deeks JJ, Sheldon TA, et al. Home parenteral nutrition: a systematic review. Health Technol Assess 1997;1:i–iii, 1–59.
15 NHS National Commissioning Group for Highly Specialised Services. A strategic framework for intestinal failure and home parenteral nutrition services for adults in England. NHS National Commissioning Group for Highly Specialised Services, 2008. http://www.specialisedservices.nhs.uk/library/28/Strategic_Framework_for_Intestinal_Failure_and_Home_Parenteral_Nutrition_Services_for_Adults_in_England_1.pdf
16 Smith T. Adult home parenteral nutrition. In: Smith T ed Annual BANS report 2011: artificial nutrition support in the UK 2000–2010. Redditch: BAPEN, 2011:27–36.
17 Department of Health. High quality care for all: NHS next stage review final report. 2008.
18 NICE. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE clinical guideline 138. London: NICE; 2012. http://www.nice.org.uk/nicemedia/live/13668/58283/58283.pdf
19 Jeejeebhoy KN, Langer B, Tsallas G, et al. Total parenteral nutrition at home—studies in patients surviving 4 months to 5 years. Gastroenterology 1976;71:943–53.
20 Greig PD, Jeejeebhoy KN, Langer B, et al. A decade of home parenteral-nutrition. Gastroenterology 1981;80:1164–64.
21 Rault RMJ, Scribner BH. Treatment of Crohn's disease with home parenteral nutrition. Gastroenterology 1977;72:1249–52.
22 Fleming CR, Beart RW, Berkner S, et al. Home parenteral-nutrition for management of the severely malnourished adult patient. Gastroenterology 1980;79:11–8.
23 Byrne WJ, Ament ME, Burke M, et al. Home parenteral nutrition. Surg Gynecol Obstet 1979;149:593–99.
24 Craig R, Neumann T, Yokoo H, et al. Alcoholic-like liver disease with severe short bowel syndrome maintained on home parenteral nutrition. Gastroenterology 1978;74:1022–22.
25 Price BS, Levine EL. Permanent total parenteral nutrition: psychological and social responses of the early stages. JPEN1979;3:48–52.
26 Perl M, Peterson LG, Dudrick SJ, et al. Psychiatric effects of long-term home hyperalimentation. Psychosomatics 1981;22:1047–63.
27 WHO. WHOQOL: measuring quality of life. Geneva: WHO, 1997. http://www.who.int/mental_health/media/68.pdf
28 Calman KC. Quality of life in cancer-patients—an hypothesis. J Med Ethics 1984;10:124–27.
29 Herfindal ET, Bernstein LR, Kudzia K, et al. Survey of home nutritional support patients. JPEN1989;13:255–61.
30 Carlsson F, Bosaeus I, Nordgren S. Quality of life and concerns in patients with short bowel syndrome. Clin Nutr 2003;22:445–52.
31 Ladefoged K. Quality of life in patients on permanent home parenteral-nutrition. JPEN 1981;5:132–37.
32 Detsky AS, McLaughlin JR, Abrams HB, et al. Quality-of-life of patients on long-term total parenteral-nutrition at home. J Gen Intern Med 1986; 1:26–33.

33 Bergner M, Bobbitt RA, Carter WB, et al. The sickness impact profile: development and final revision of a health status measure. Med Care 1981;19:787–805.
34 Jeppesen PB, Langholz E, Mortensen PB. Quality of life in patients receiving home parenteral nutrition. Gut 1999;44:844–52.
35 Pironi L, Paganelli F, Mosconi P, et al. The SF-36 instrument for the follow-up of health-related quality-of-life assessment of patients undergoing home parenteral nutrition for benign disease. Transplant Proc 2004;36:255–58.
36 Persoon A, Huisman-de Waal G, Naber TA, et al. Impact of long-term HPN on daily life in adults. Clin Nutr 2005;24:304–13.
37 Richards DM, Scott NA, Shaffer JL, et al. Opiate and sedative dependence predicts a poor outcome for patients receiving home parenteral nutrition. JPEN 1997;21:336–38.
38 Carlson GL, Maguire G, Williams N, et al. Quality of life on home parenteral nutrition—a single-center study of 37 patients. Clin Nutr 1995;14:219–28.
39 Reddy P, Malone M. Cost and outcome analysis of home parenteral and enteral nutrition. JPEN 1998;22:302–10.
40 Baxter JP, Fayers PM, McKinlay AW. A review of the instruments used to assess the quality of life of adult patients with chronic intestinal failure receiving parenteral nutrition at home. Br J Nutr 2005;94:633–38.
41 Orrevall Y, Tishelman C, Permert J. Home parenteral nutrition: a qualitative interview study of the experiences of advanced cancer patients and their families. Clin Nutr 2005;24:961–70.
42 Huisman-de Waal G, Naber T, Schoonhoven L, et al. Problems experienced by patients receiving parenteral nutrition at home: results of an open interview study. JPEN 2006;30:215–21.
43 Smith CE. Quality of life in long-term total parenteral nutrition patients and their family caregivers. JPEN 1993;17:501–6.
44 Silver HJ. The lived experience of home total parenteral nutrition: an online qualitative inquiry with adults, children, and mothers. Nutr Clin Pract 2004;19:297–304.
45 Winkler MF, Hagan E, Wetle T, et al. An exploration of quality of life and the experience of living with home parenteral nutrition. JPEN 2010;34:395–407.
46 Baxter JP, Fayers PM, McKinlay AW. The clinical and psychometric validation of a questionnaire to assess the quality of life of adult patients treated with long-term parenteral nutrition. JPEN 2010;34:131–42.
47 Malone M. Home parenteral nutrition: effect of patients' lifestyle. Clin Nutr 1989;8:11–13.
48 Carter DM, Wheatley C, Payne-James JJ, et al. Home nutrition survey in the UK: the patient's perspective. Clin Nutr 1993;12:208–12.
49 Elia M, Stratton RJ, Holden C, et al. Home artificial nutritional support: the value of the British Artificial Nutrition Survey. Clin Nutr 2001;20:61–6.
50 Fortune DG, Varden J, Farker S, et al. Illness beliefs of patients on home parenteral nutrition (HPN) and their relation to emotional distress. Clin Nutr 2005;24:896–903.

Appendix 2 Literature review search strategies

Medline (January 1970 to December 2013)

MESH terms were used where they were available.

Search terms used:

1. Home parenteral nutrition (MESH term: Parenteral Nutrition, Home Total)
2. Intestinal failure (MESH term: Intestinal Perforation)
3. Patient Experience
4. Quality of Life

Search term	Results
1	2
2	46
1 and 2	2
1 and 3	2
1 and 4	6955
2 and 4	7000
2 and 3	6600
1 and 3 and 4	5461

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CINAHL (Cumulative Index to Nursing and Allied Health Literature) (January 1970 to December 2013)

Keywords were used where they were available.

Search terms used:

1. Home parenteral nutrition (standard keyword in database: home nutrition support, total parenteral nutrition)
2. Intestinal failure (standard keyword in database: intestinal fistula)
3. Patient experiences
4. Quality of life

The search was restricted to full text publications only.

Search term	Results
1	40
2	4
1 and 2	40
1 and 3	40
1 and 4	3177
1 and 3 and 4	1654

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Web of Science (formerly Wed of Knowledge)(January 1970 to December 2013)

Keywords were used where they were available.

Search terms used:

1. Home parenteral nutrition
2. Intestinal failure
3. Patient experiences
4. Quality of life

The search was restricted to full text publications only.

Search term	Results
1	223
2	1541
1 and 2 and 3	15
1 and 2 and 3 and 4	4

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Publications from specialist journals

Parenteral nutrition is a specialised clinical practice. Research literature and studies published by international and national professional journals and by

societies were considered if they had been identified by the selected electronic databases using the same or similar search terms. These journals cover a range of healthcare professions: medical, surgical, nursing and pharmacy reflecting the multidisciplinary nature of HPN treatment.

Articles from following journals were reviewed:

- Clinical Nutrition
- Journal of Parenteral and Enteral Nutrition
- Gastroenterology
- Gut
- Journal of American Medical Association
- Scandinavian Journal of Gastroenterology
- Proceeding of the Nutrition Society
- Annual of Surgery
- Lancet
- Journal of Internal Medicine
- British Journal of Nutrition
- Nutrition in Clinical Practice
- Publications from specialist groups

The following registered charitable organisations have prepared documents, reports and publications which are used by NST and clinical commissioning groups:

- British Artificial Nutrition Survey (BANS) (on behalf of the British Association of Parenteral and Enteral Nutrition, BAPEN)
- Patients on Intravenous Nutrition and Naso-Gastric Therapy (PINNT)

Publications from the Department of Health websites

- National Institute of Health and Clinical Excellence (NICE)

Qualitative research studies

A number of articles, guidance and checklists were used to support the critical appraisal of studies identified from the literature search (Pope and Mays, 1995, Greenhalgh et a., 1997, Kuper et al., 2008). The following questions were used when reviewing the published literature:

- Is the purpose of the study / research question clearly identified?
- Does the researcher indicate a degree of knowledge in the field being studied?
- Has a literature review been undertaken?
- Is the sampling method appropriate?
- Are the participants appropriate for the study?
- Are the participants fully informed about the nature of the research?
- Has ethical permission been granted for the study?
- Has the researcher described the data collection strategies?
- Has the researcher discussed how the rigor was assured?
- Are the findings reflected in the conclusion?
- Has the researcher discussed limitations of the study design and findings?

Quantitative research studies

During the literature search the quantitative studies identified were using questionnaire as the method of data collection. Therefore, some elements of the checklist prepared by Creswell (2003, p.155) were used to support the critical appraisal process:

- Is the purpose of the study / research question clearly identified?

- Does the researcher indicate a degree of knowledge in the field being studied?
- Has a literature review been undertaken?
- Is the sampling method appropriate?
- Are the participants appropriate for the study?
- Is the purpose of the questionnaire chosen stated?
- Has the researcher described how the questionnaires were distributed to the participants, and how the completed ones were collected?
- Has the researcher discussed reliability of the questionnaires?
- Are the findings reflected in the conclusion?
- Has the researcher discussed limitations of the study design and findings?

Appendix 3 Recruitment poster

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Sheffield Teaching Hospital NHS Foundation Trust
Clinical Research Study

As a user of the Home Parenteral Nutrition Service, would you be interested in taking part in a study which looks at the impact of HPN on quality of life?

The researcher will be carrying out interviews with individual patients and she wants to hear your story of living with HPN.

If you are interested in taking part, the researcher will be available at the HPN clinic to explain to you the study and to answer your questions.

You can contact Christina Wong for further information:
Telephone: 0114 2714502 or
0114 434343 long range pager
Email: Christina.wong@sth.nhs.uk

Appendix 4 Invitation letter

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Research study: Home parenteral nutrition in South Yorkshire: a qualitative study exploring the views and experiences of adult patients

Dear Sir / Madam

I am writing to ask if you would be interested in taking part in this research study. The researcher will carry out an interview with each patient who is on home parenteral nutrition (HPN). From this we will gain insight from the patient's perspectives and this will help us to understand better what it is like living with HPN and taking medications long term. Your views are important and the study findings will help us to improve our service to other HPN patients.

Approval for the study has been obtained from the **NRES Committee North West – Greater Manchester North** (REC reference number 12/NW/0554) and the Sheffield Teaching Hospitals NHS Foundation Trust's Research Department (STH 16314).

We will interview you at home. It will take approximately one hour and it will be audio-taped. Patient confidentiality will be maintained throughout the interview. Patient identifiable information will not be included in the transcriptions or final report of this study.

The **'Participant Information Sheet** for the study gives you more details about what we want to do. Ask us if there is anything that is not clear. I will be available to answer your questions at the HPN clinic. Please take some time to think about this before making up your mind. If you wish to take part in this study, please give me a ring at the Northern General Hospital on 0114 2715543 during office hours from 8.30am to 5pm Mondays to Fridays.

I look forward to meeting you at the HPN clinic.

Yours sincerely

Christina Wong
Consultant Pharmacist (BPharm, GPhC, Dip Clin Pharm, IPrec),
Chief investigator, Pharmacy department, Northern General Hospital, Herries Road, Sheffield S5 7AU
Email: christina.wong@sth.nhs.uk

Appendix 5 Participant information sheet for competent adults

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Study Title: Home Parenteral Nutrition in South Yorkshire: a qualitative study exploring the view and experiences of adult patients

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REC Reference Number: 12/NW/0554

STH Research Number: STH 16314

Name of Researcher (&Chief Investigator): Christina Wong

Date: August 2012

PART ONE

Invitation paragraph

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. The chief investigator will be available at the home parenteral nutrition (HPN) out-patient clinic to go through the information sheet with you and answer any questions you have. We'd suggest this should take about 20 minutes. Talk to others about the study if you wish.

What is the purpose of the study?

The purpose of the study is to find out how you cope with home parenteral nutrition and complex medication regimens in the community. We also want to find out how the current nutrition support service provided by the hospital meets the patients' needs.

Why have I been invited?

This study is open to all adult patients who are able to give informed consent and are currently receiving HPN feeds alone, a combination of HPN feeds and intravenous fluids, or intravenous fluids alone.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

Once you have given written consent, the chief investigator will contact you via telephone and arrange a convenient date and time for an interview at your home. This will take place during weekdays at normal office hours between 9am and 5pm.

Expenses and payments

There is no external commercial funding for this study and no payment will be made to the research team or the participants.

What will I have to do?

Each participant will be interviewed once. During the one to one interview the chief investigator will ask you a number of questions around HPN and taking medications long term. We want to learn about the patients' perspectives so your views are important to us. The interview will take approximately 1 hour and it would be taped using a Dictaphone. The research may take written notes during the interview. The researcher will explain to the participant that he / she may push the pause button on the Dictaphone at any time. This gives interviewees control over the recording process if they need time to consider their response to a particular question. There is no follow-up visit after the interview.

What are the possible disadvantages and risks of taking part?

There are no possible disadvantages and risks of taking part. The chief investigator will offer to play back the tape at the participants' request if they feel what they said did not reflect their real feelings, or these were not expressed accurately in the way they intended.

Radiation and Ionising Radiation (Medical Exposure)

Not applicable to this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the service to people who are dependent on HPN.

What happens when the research study stops?

The chief investigator will destroy all study materials once the contents have been analysed and the written report is complete. Patient identifiable information will not be included in the transcriptions or the final report. Each participant will be offered a written copy of the research findings if they wish to receive it. We will share the study findings with the nutrition support team and local health service providers. The researcher also plans to publish the findings in a healthcare journal. (Pending successful ethics approval, the following

statement will be included). All research in the NHS is looked at by independent group of people, called a Research Ethics Committee (REC), to protect your interests. This study has been reviewed and given favourable opinion by the NRES Committee North West – Greater Manchester North.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible upset you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled with confidence. The details are included in Part 2.

This completes Part One.

PART TWO

What if relevant new information becomes available?

If this study is stopped for any other reason, it will not affect the care you receive from the Nutrition Support Team at the Royal Hallamshire Hospital.

What will happen if I don't want to carry on with the study?

If you don't want to carry on with the study, you need to tell the chief investigator as soon as possible. If this happens before the interview, you can contact the chief investigator by phone on 0114 2715543, by email christina.wong@sth.nhs.uk or in writing to Christina Wong, Pharmacy Department, Northern General Hospital, Herries Road, Sheffield S5 7AU. If this happens during the interview, you need to tell the chief investigator who will stop the interview recording. The information already given by the participant will not be used in the data analysis. The recording and any written notes taken will be destroyed in accordance with the hospital's policy on disposal of confidential information.

What if there is a problem (I have a complaint)?

If there is a problem or you have a complaint, you should ask to speak to the chief investigator who will do her best to answer your questions (Telephone number 0114 2715543 or Email christina.wong@sth.nhs.uk). If you remain unhappy and wish to complain formally, you can do this by following the Sheffield Teaching Hospitals NHS Foundation Trust's 'Concerns and Complaints Policy'. Details can be obtained from Sue Butler, Head of Patient Partnership, Patient Partnership Department, B Floor, Royal Hallamshire Hospital,

Glossop Road, Sheffield S10 2JF. Telephone number 0114 2711766 or email sue.butler@sth.nhs.uk

Will my taking part be kept confidential?

Yes. All information collected during the course of the research will be kept strictly confidential. Your name and other personal details will not be used during the interview. All hand written notes taken during interview and audio-tapes will be kept in a lockable filing cabinet in the hospital pharmacy. The chief investigator is the only person who has access to these materials. She will type the transcripts and notes taken during the interviews. These will be saved on the hospital pharmacy computer S-drive under the chief investigator's name with user name and password restriction. The chief investigator may include direct quotations from the participants' interview in the transcriptions, final report and doctoral thesis. These will not contain the participants' names or other identifiable information.

The transcriptions may also be looked at by the researcher's academic supervisors at the University of Bradford to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. Participants have the right to check the accuracy of transcriptions and correct any errors. Please let the chief investigator know if you wish to do this. The transcriptions and audio-tapes will not be retained for any length of time after the final report has been completed. These will be destroyed in accordance with the hospital's policy on disposal of confidential information. Data collected during the study will not be shared with other researchers in this or other countries.

Will my General Practitioner (GP) or other healthcare professional be notified?

No. This study does not affect the care you receive from your GP or the Nutrition Support Team at Royal Hallamshire Hospital.

What will happen to the results of the research study?

The findings form this study will be presented locally to the Nutrition Support Team members. They will also be presented nationally at nutrition meetings (e.g. British Association for Parenteral and Enteral Nutrition, BAPEN and British Pharmaceutical Nutrition Group, BPNG). The chief investigator also plans to submit this for publication in a high impact factor peer-reviewed journal (E.g. Journal of Parenteral and Enteral Nutrition or Clinical Nutrition). A paper or electronic copy of the research summary will be made available to the participants and other HPN patients on request. The STH Research Department may wish to publish the findings as part of the Trust's Research & Development

programme. In addition, the chief investigator will include the data analysis and findings in a postgraduate (Doctor of Pharmacy) thesis for submission to the University of Bradford.

Who is organising and funding the research?

There is no external or commercial funding sourced by the chief investigator. The hospital pharmacy department is funding the research in the form of staff salary and travelling expenses.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee North West – Greater Manchester North.

Further information and contact details

General information about research

You can find out more about NHS research and public involvement from the website www.involve.org.uk

Specific information about this research project

You can contact the chief investigator, Christina Wong, by telephone on 0114 2715543 or by email christina.wong@sth.nhs.uk.

Advice as to whether they should participate

You may wish to discuss this with the chief investigator, Christina Wong (see above) or any member of the Nutrition Support Team at the Royal Hallamshire Hospital (see below).

Who they should approach if unhappy with the study

In the event that you are unhappy with the study or felt upset and unsettled following the interview, you may wish to contact the chief investigator, Christina Wong or a member of the Nutrition Support Team at the Royal Hallamshire Hospital:

Name	**Telephone number**	**Email address**
Christina Wong (chief investigator)	**0114 2715543**	**christina.wong@sth.nhs.uk**
Dr Mark McAlindon	**0114 2712443**	**mark.mcalindon@sth.nhs.uk**
Dr Kevin Page	**0114 2712787**	**kevin.page@sth.nhs.uk**
Mrs Hazel Saddington	**0114 2766355**	**hazel.saddington@sth.nhs.uk**

Mrs Sue McIlroy **0114 2766355** **–sue.mcilroy@sth.nhs.uk**

Appendix 6 Participant consent form

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

STH Study Number: STH 16314

REC Reference Number: 12/NM0554

CONSENT FORM FOR COMPETENT ADUTLS

Study title: Home Parenteral Nutrition in South Yorkshire: a qualitative study exploring the views and experiences of adult patients

Name of Researcher: Christina Wong **Please initial box if you agree**

1. I confirm that I have read and understand the information sheet dated 01/08/2012 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the Northern General Hospital, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. I agree to take part in the above study. ☐

6. I agree for the interview to be audio-taped. ☐

7. I agree for the interview to be transcribed. ☐

8. I agree for anonymised direct quotations to be used. ☐

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

When completed: 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 7 Interview guide (Winkler et al., 2010, Kvale, 2007, Silver, 2004)

1	Tell me about how you came to receive home parenteral nutrition?	
2	Tell me your story of what it is like to be on home parenteral nutrition? Probes (if needed) How does being on home parenteral nutrition affect your everyday life? What things are bad about being on home parenteral nutrition? What could be better? If respondent mentions any problems, complaints, or symptoms, ask whether these are related to the therapy, equipment, or stated medical condition.	
3	Tell me how your life is different with home parenteral nutrition? Probe (if needed) Tell me about the changes you have made in your life because you are on this treatment.	
4	Tell me about any fears you have related to receiving home parenteral nutrition. Probe (if needed) Are these fears related to handling the feed solution?	
5	Do you have any symptoms or problems that interfere with your enjoyment of life?	
6	What does the term quality of life mean to you? How would you describe your own quality of life? Probes (if needed) If there are multiple components to quality of life, explore how respondent would order or rank them.	
7	Does parenteral nutrition influence your quality of life? If so, please describe. Probes (if needed) Describe quality of life before you were on home parenteral nutrition and now that you have been on home parenteral nutrition.	
8	How much does your (stated medical condition) contribute to your quality of life?	
9	Let's talk about eating and drinking; what can you tell me about this?	

	Probes (if needed) Tell me about the foods you eat and the ones you don't. How do you handle the diet restrictions you have?	
10	For participants with high output ileostomies and are taking proton pump inhibitors (omeprazole or lansoprazole), loperamide and or codeine: Probes (if needed) How long have you been taking these medicines? What can you tell me about your experience with taking medicines to slow down the output from the stoma? Do you feel you have benefited from taking the medication? In what ways? Have you had any problems with the medications? What were they? How serious do you think they were? Are you happy with your prescribed medication? What would you change if it were possible?	
11	Is there anything you wish you had been told about before you started on home parenteral nutrition? Probe (if needed) Are there things that you feel you are missing?	
12	Can you tell me if there has been anything that has happened in the last few days that might have influenced your responses?	
13	Please summarise what home parenteral nutrition means to you in a brief statement.	
14	Is there anything else you would like to tell me about, related to being on home parenteral nutrition?	

Appendix 8 Modified interview guide (Winkler et al., 2010, Kvale 2007, Silver, 2004)

1	Can you tell me what happened to you and why you are on this treatment at home? Probes How long did it take you to come round from the initial surgery and to think about what is happening?	
2	Stoma (& training): What was your first memory of having a stoma? Probes (if needed) How did you come to terms with having to manage the stoma? Tell me how you coped with the ileostomy. How did you manage any incidents that you could remember? Do you feel you were prepared with what to expect? Tell me about the next stage of your recovery. What can you remember?	
3	HPN / IV fluids Can you remember how the news was given to you that you need to carry on this treatment at home? Tell me more how you reacted to the news. Probe (if needed) Tell me about any fears you have related to receiving home parenteral nutrition. Tell me about the changes you have made in your life because you are on this treatment. Having to live with stoma and tpn, which of the two do you find most troublesome? How does being on home parenteral nutrition affect your everyday life? What things are different with home parenteral nutrition? What could be better? How does your family cope with you being on home tpn? If respondent mentions any problems, complaints, or symptoms, ask whether these are related to the therapy, equipment, or stated medical condition.	
4	Do you have any symptoms or problems that interfere with your enjoyment of life?	
5	Going home: Now I want you to tell me how you felt the first day you came back from hospital and the first time you have all the equipment and feeds delivered. When the front door closed, can you remember how you felt Probes (if needed) How do you find the impact of home tpn on the way you live? How many nights are you having the infusion? Did you feel you could do with some help? How would you describe the impact of this treatment on your social life? Could you describe the impact of this on your enjoyment of life?	
6	Self-help groups: Were you offered any information about patient self-help groups? Can you remember the name? Does parenteral nutrition influence your quality of life? If so, please describe. Probes (if needed) Describe quality of life before you were on home parenteral nutrition and now that you have been on home parenteral nutrition.	

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7	Quality of life: How much does your (stated medical condition) contribute to your quality of life? What does the term quality of life mean to you? How would you describe your own quality of life? If there are multiple components to quality of life, explore how respondent would order or rank them.		Formatted: Font: 10 pt
8	Let's talk about eating and drinking; what can you tell me about this? Probes (if needed): Can you remember at what stage you were given specific advice on diet? Tell me about your diet (the foods you eat and the ones you don't / can't). How do you find the diet? How do you feel about the dietary restrictions? Tell me how you coped with this. Did the dietitian give you reasons why that were important to follow the advice?		Formatted: Font: 10 pt
9	For participants with high output ileostomies and are taking proton pump inhibitors (omeprazole or lansoprazole), loperamide and or codeine: Probes (if needed): How long have you been taking these medicines? What can you tell me about your experience with taking medicines to slow down the output from the stoma? Do you feel you have benefited from taking the medication? In what ways? Have you had any problems with the medications? What were they? How serious do you think they were? Are you happy with your prescribed medication? What would you change if it were possible?		Formatted: Font: 10 pt
10	HPN clinic: How do you find the HPN clinic? Tell me if there is anything you want to change about the clinic.		Formatted: Font: 10 pt
11	Is there anything you wish you had been told about before you started on home parenteral nutrition? Probe (if needed): Are there things that you feel you are missing?		Formatted: Font: 10 pt
12	Can you tell me if there has been anything that has happened in the last few days that might have influenced your responses?		Formatted: Font: 10 pt
13	Please summarise what home parenteral nutrition means to you in a brief statement.		Formatted: Font: 10 pt
14	Is there anything else you would like to tell me about, related to being on home parenteral nutrition?		Formatted: Font: 10 pt

Appendix 9 Permission for recruitment of participants

Dear Christina
I am happy to support this research proposal from my perspective as clinical Director, Gastroenterology and Hepatology
I wish you every success
Best wishes
Mark

From: Wong, Christina (Pharmacy)
Sent: 21 February 2012 16:01
To: Donnelly, Mark (Gastroenterology)
Cc: McAlindon, Mark (Gastroenterology); Page, Kevin (Clinical Chemistry)
Subject: HPN study proposal final version

Dear Mark

I am the process of setting up a research study with our HPN patients – the plan is to start this in early summer. This is part of the DPharm course with the University of Bradford.

I am meeting my academic supervisors to finalise this on Thursday 1st March. After this meeting, I am hoping to submit the proposal to IRAS for Sheffield NRES committee meeting on 2nd April.

In order to meet the STH Research dept's requirements, I need written approval from you, as clinical director for gastroenterology, for me to recruit patients from the HPN clinic.

Please find attached a copy of the study proposal. I hope you have time to a have a look at this before the middle of March. Once you are happy with this, it is acceptable for you to send me an email reply indicating your approval for the study.

Please give me a call or send me an email if you any questions.

Thanks

Christina

Appendix 10 Participant interview log

Participant Number	Participant Initials	Participant Contact Phone Number	Participant Home Address	Interview Date & Time	Time chief investigator phoned to confirm arrival at participant's home (00.00hr)	Time chief investigator phoned to confirm departure from participant's home (00.00hr)	Initials of pharmacy secretary who has taken the phone message (data & time)

Chief investigator mobile phone number: 07966 184089

Appendix 11 Theoretical memo - open data exploration on stoma and HPN

Interview date 18.10.2012 P#1 20.10.2012

This was my first research interview so I was very nervous at the beginning. I struggled to follow the questions on the interview guide and listen to what the participant was saying at the same time. There were frequent pauses and it interrupted the flow of the conversation. The participant seemed more at ease than me in telling me her story. As I listened to her story and focused on what she was saying, I became less nervous and was able to maintaining the conversation naturally.

As I was typing the transcription, I could hear the frustration in her voice as she described her life with the stoma and HPN. What happened to her from a fall and a broken ankle led to life threatening complication. She had no choice but to undergo emergency operation which resulted in the formation of an ileostomy. During the course of the interview, she mentioned several times her feelings on having to live with stoma and HPN at home. She described in details things that she did not like. She seemed dissatisfied with life in many ways both at home and socially.
She was well informed by the surgeon of the risk with further surgery but she had decided that this was what she desperately wanted. She was determined to press ahead with the operation to 'get rid of stoma'.
'Sudden Illness'

'I had a blood clot in my leg and then I had a blood clot in my bowels the same night. But previous to those 8 weeks ago I broke my leg so I had a third operation. I got a blood clot in my bowel and they had to do a stoma to get rid of blood clot' (#1, p1)

P#1 described her experience with 'sudden illness' – a broken ankle from a fall, she then developed blood clots after the ankle surgery leading to serious, life-threatening condition affecting her leg and her bowels. Her description illustrated the properties of 'Sudden Illness': 'Severity' and 'Treatment'. The detailed account of her experiences illustrated the dimensions for these two properties.

'Severity' She had a blood clot affecting blood supply to her bowels – this was 'life threatening'. She needed abdominal surgery to remove the clot (negative experience).

'Treatment' She didn't have a choice in treatment option as it was life-threatening. From the surgery she was left with a 'stoma'. Her stoma losses caused other health problems and she needed 'total parenteral nutrition' (TPN) at home in order to maintain health.

P#1's eyesight was also affected as the result of her underlying health condition. She became dependent on her husband as her main carer in setting up the TPN at home. Her story was full of details on living with a 'stoma' and 'TPN'.
Her story had many personal and emotional experiences on the impact of stoma and TPN on health, life style and choices. She described in details how she tried to accommodate everything when she was at home and when she was going out. She described the adverse effect of TPN on the liver but she was determined to go ahead with surgery to restore bowel continuity:

'….so I'm glad actually they are saying that I've got to come off so it's pushing me for surgery a bit more' (#1, p.2)

'I want to get the operation. And then I want to, if I can, I can then / I might get off fluids, if I get rid of stoma, I might get rid of the problem' (#1, p.9)

Living with 'Stoma' 22.10.2012

P#1 described how she lived with the stoma. The following excerpts illustrated two main properties of the 'Stoma': 'Characteristics' and 'Coping Strategies'.

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'And because the outcome of the stoma was such a great amount and I weren't keeping any fluids and you know what I mean, they suggested that I go onto tpn (total parenteral nutrition), fluids at first and then overtime we're going to feed some fluids but I think it was the feeds that was somewhere along the line it's not actually suiting me because it's affecting my liver and Dr P had a word with me and he said that long term fluids are no good for me. ' (#1, p.1)

The stoma losses were so high that it reduced the 'digestion of food' causing 'problems with general health' from malabsorption. She was told by the doctor that she needed TPN but this should only be for short term because of its harmful effects on the liver.

'….when you go out, I have to wear dark cloths in case stoma goes. If I am wearing something like pale blue and stoma goes it's just going to come through. I'm always concerned about bag leak' (#1, p4).

'I have to pick what clothes to wear so I have dark clothes on when I'm going out' (#1, p.11)

'I can't carry shopping and I couldn't go on my own. I won't go down to Hillsborough or anywhere on my own because people are coming in front of you like this way and I don't see them' (#1, p.18)

On a 'social level' she wore dark colours and this limited her 'choice' of colours that provided 'disguise' should the stoma leaked. With the stoma bag on, she needed help to carry the shopping. She had impaired vision in one eye and this had limited her ability to go out on her own.

'When I am going out to things like that, I am always a little bit unsure about the stoma, do you know what I mean, it's either come off or fallen out' (#1, p.10)

'O god I can remember if I have something to eat, I can go to the toilet and empty this bag twenty times a day' (#1, p.11)

'If I'm going to hospital or I'm going out, an appointment or whatever, I don't have anything to eat because of this stoma because I am forever at the toilet' (#1, p.11)

'I'm so restricted ……. plan around stoma and ….you empty stoma and then at eight o'clock you go to bed with tpn and stoma, and then when you get in bed you got night bag on and you got stoma and you got Hickman line – I don't…...it's not very…….I probably think I'm a lot younger than I am you know' (#1, p.16)

'I mean I don't want sexy nighties you know what I mean, but I would like something a bit more, a bit more ….. what do they call them ….a bit more nicer you know what I mean' (#1, p.16)

'I mean you just adjust, don't you, you adjust to it, you got to adjust' (#1, p.19)

'I found it really overwhelming at first. But you do, you do adjust don't you. Like a routine isn't it, everything is like a routine' (#1, p.19)

On an 'emotional level' she worried about leaks from the stoma a lot and this became a source of 'anxiety' when she went out. She felt a sense of 'lack of control' over 'stoma losses' and the 'frequency' to empty the bags. She found everything overwhelming but she showed determination in putting up with the 'routine'.

'you go to the toilet to empty stoma and you're carrying that to toilet, oh and then at night you got night bag on and then you got tpn stuff you know what I mean, you feel a bit.. you don't feel… you feel unattractive do you know what I mean, with all this on' (#1, p.4)

'To keep off….what they call them like bran things, you know like…. Weetabix and things like that. I think it's just, it's going to make stoma come out more with bran' (#1, p.9-10)

'They say I can have cornflakes or rice crispy and I quite like rice crispy so I haven't got a problem with that. Erm, vegetables, cauliflower, carrots, and turnips you can have them but you have to be careful with them' (#1, p.10)

'I can have tinned spaghetti on toast, and I can be eating that and I can go to toilet and before I finish eating the spaghetti is down the toilet in stoma' (#1, p.10)

'It passes out so fast the spaghetti, I don't know why. You know when I have gone to the toilet I actually saw what I am eating on the plate in the toilet at the same time' (#1, p.10)'

I'm not very good at meals. I have to fancy meals and I'm not, I can't say I have a very good appetite' (#1, p.10)

'All my friends are quite understanding and they, you know, they say 'I don't know how I'll cope If I were the same as you'. I just think, don't think I could cope' (#1, p.17)

'Yes, but you just got to, you just got to cope haven't you' (#, p.17)
'I don't know, I think I got inner strength in me, must have' (#1, p.17)

On a 'dietary level' she refrained from certain foods because she could not digest or absorb them properly. This 'avoidance' approach was necessary so that losses from stoma did not become excessive and unmanageable. She was aware of the 'restriction' on which vegetables to have. She described vividly the 'shock' of seeing undigested foods in the stoma bag when she emptied it. The problem of food 'malabsorption' had affected her appetite in general.

'Sometimes if you are travelling you have to sit in front so you can stretch your legs so you are not cramped up because if you sit cramped, it comes off sometimes, the bag' (#1, p.11)

'You have to be careful what to wear, be careful where you go because I need toilets. I want to go somewhere with a lot of toilets' (#1, p.11-12)

'Oh they have been….they have been pretty good. Any where I want to go they don't have a problem' (#1, p.18)

'I mean I can put washing out, you know things like that, but I am careful when I do it but I'm a lot, a lot slower obviously than I were before but I do cope pretty good really.#' (#1, p.19)

She was 'resourceful' when planning a car journey – she would not eat before going on a car journey, and she would take up the front seat in a car in order to minimise leaks from stoma bag. She was proud to be able to put the washing out be it slowly as she was aware of her physical limitations.

Medications and stoma management (Positive experiences)
'Yeah, like Imodium but it's not called Imodium. Three of them, no, four of them, six of them four times a day. To slow stoma down a little bit' (#1, p.5)
'Horrible. You know Dioralyte, Dioralyte. I couldn't, I couldn't stomach it… I don't know, I just didn't, couldn't' get on with it…I just told them I didn't like it…' (reference to medications to reduce stoma losses) (#1, p. #15)

'I always take my take my medications on time, take it with water, I don't need anybody taught me to do that' (#1, p.19)

'I have to have them (loperamide) in powder so I take them in water, I have six of them four times a day and two codeine four times a day' (#1, p.5)

She was 'well informed' of what Imodium (loperamide) did ('to slow down stoma output') and she 'understood the special instructions' on how to take them. She disliked the taste of Dioralyte oral electrolyte solution and it was 'her own decision' not to take this.

Medications and stoma management (Negative experiences)
'I'm thinking is it going to flush toilet, do you know what I mean. And it's always things in your mind, 'I hope it's going to flush this toilet before I go out' (#1, p.12)

'I've used the toilets there and they haven't flushed. It's awful and I don't like it. I find it right degrading' (#1, p.12)

'I can go to my daughter from my daughter to Meadow Hall, and I have to use toilets four times on the way there. It's a bind but it's the stoma that is a bind' (#1, P.13)
'Going out, yes. Anywhere – Meadow Hall wherever. I think a lot of that is to do with stoma than tpn actually' (#1, P.16)

'I mean I don't want sexy nighties you know what I mean, but I would like something a bit more, a bit more ….. what do they call them ….a bit more nicer you know what I mean' (#1, p.16)
She described the intensity of her 'anxiety' over the efficiency of toilets to flush properly after use. She had experience with toilet mal-function after use and she was filled with 'embarrassment' leaving her 'feeling degraded'. Her 'frustration' was with the uncertainty of leaks from the stoma and the need to have access to toilets quickly to empty the bag. She blamed the stoma for the anxiety. She found the 'lack of choice' of nighties a real issue. She described her disappointment / frustration of not being able to wear nighties which she liked as they were impracticable when she had to have the stoma bag on and the feed bag attached to the Hickman line at night.

From these excerpts I identified the dimensions of 'Stoma Characteristics' and 'Stoma Coping Strategies'

'Stoma Characteristics'
Dimensions

- Volume and frequency – high volumes and unpredictable frequencies
- Undigested food – reduced absorption (problems with chronic deficiencies of micro- and macronutrients)

'Stoma Coping Strategies'
Dimensions

- Social - 'Choice' of clothing to 'disguise' leaks from stoma bag. This was limited to dark colours so that leaks from stoma were less noticeable.
- Emotional – 'Anxiety' over leaks from stoma bags; 'embarrassment' with toilet mal-function whereby undigested foods were not flushed away; 'lack of control' over the 'stoma losses' and 'frequency' to empty the bags.
- Dietary - 'Avoidance' approach was necessary so that losses from stoma did not become excessive and unmanageable; awareness of the 'restriction' on which vegetables to have; 'shock' of seeing undigested foods in the stoma bag; problem of food 'malabsorption' had affected her appetite in general.

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Living with 'Home Parenteral Nutrition (HPN)' 12.11.2012

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'…. *they suggested that I go onto tpn, fluids at first and then overtime we're going to feed some fluids but I think it was the feeds that was somewhere along the line it's not actually suiting me because it's affecting my liver and Dr P had a word with me and he said that long term fluids are no good for me. I can only be on short term*' *(#1, p.1)*

'Dr P said because these fluids are not suiting me I am talking two or three years right at the most and then I will start going jaundice then' (#1, p.1-2)

'I won't be in pain but I'll be going jaundice and my liver will give up do you know what I mean... they say my liver will pack up' (#1, p.2)

'so I'm glad actually they are saying that I've got to come off so it's pushing me for surgery a bit more' (#1, p.2)

P#1 was told by the doctor that she would develop jaundice from being on HPN long term. She was well informed of this health complication. With this information she became more determined in having the operation to remove the stoma.

During the first part of the interview, P#1 gave a detailed description on how she lived with HPN and how she was tried to maintain a social life around the treatment routine. Her description illustrated the properties of living with 'TPN': 'HPN Characteristics' and 'HPN Coping Strategies' 'HPN Characteristics' .
P#1 suffered poor sight in one eye meant that she could not connect the administration set to the Hickman line and to operate the infusion pump safely. She needed help from her husband who set up the HPN feed to the infusion pump at night. He became the main carer for her and she's 'dependent' on him.

The following excerpts illustrated the many dimensions of HPN:

Dimensions

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- **Routine (**Negative experiences)

'I don't like being on long term for twelve hours in here every day. We have not been able to go away or holiday, you know what I mean stuff like that and I find it quite binding' (#1, p.2)

'*My husband puts me on it; I have to take myself off it. I do that because he puts it on at twelve and he has to click the bottom off and it's like a blue fastener, and I find it hard for me to take that off. So Keith always does that, and then he gets that wire, Hickman mm…….that line and he changes me Hickman line. All I do is take me of it. (#1, p.4)*

'I seem to have a problem here. I was a bit [P1 rolled her eyes and appeared fed up] when I have to go on it, because then I have to carry it all night. If I go to the kitchen, I have to carry it; I want go upstairs I got to carry it upstairs. I'm just tired of it; I'm not used to being tired' (#1, p.7)

'Last night I put on it a little bit early about half past seven so I take if off at half seven today. But once day time's here, I am happy here, you know what I mean. I can get that. Just when at night time I [rolled her eyes with expression of being fed up], you know what I mean, I don't like it being restricted'' (#1, p.7-8)

'Being restricted I don't like it. It's that restrictions that I don't like' (#1, p.8)

'you find them out yourself really, don't you?' (in the context of understanding the limitations of HPN at home) (#1, p.14)

'I think it's more of a social thing for me, you can't, you can't go out, or you'll have to go out and come back and have it put on at eight or you have to wait when you come home and start putting it on. And then it's till the next day or till whenever' (#1, p.16)

'I'm so restricted ……. plan around stoma and ….you empty stoma and then at eight o'clock you go to bed with tpn and stoma, and then when you get in bed you got night bag on and you got stoma and you got Hickman line – I don't…...it's not very…….I probably think I'm a lot younger than I am you know' (#1, p.16)

She found the HPN routine 'inflexible', 'restrictive' and 'binding' as it had to start and finish at a set time. It placed limits on her social life and when she had to return home at night in time for the HPN infusion to start. She put up with the situation but she was clearly unhappy with the 'restriction'. She found the infusion pump 'restrictive' as she had to carry it with her around the house at night.

- **Health without HPN** (Negative experiences)

'If I don't get it though, I do get dehydrated I found that' (#1, p.2)

'Oh makes me tired, I can't walk upstairs and things like that and I'm really what's the word... really tired and not much appetite and literally makes me feel poorly and weak you know what I mean' (#1, p.2)

'I have tried it and they said well I can try it on a Saturday night not having it cause I said well can't I have one Saturday night just go without it' (#1, p.2-3)

'He said you can try it if you want. First time I were fine then the following Saturday, because we go out Saturday, I weren't too clever' (#1, p.3)

'I started feeling tired and me back hurt you know what I mean that pain in the back that me kidneys so I was getting a little bit dehydrated so I haven't done it since' (#1, p.3)

'If I haven't on it, I just feel dehydrated and I will end up in hospital, so I've got to be on it' (#1, P.14)

She was given the choice by her HPN team to have a trial of no HPN for one night. She felt dehydrated on the second week. This showed her 'risk-taking' nature when making a choice for herself in order to find out if she could get away without HPN for one night. Although she found the HPN routine restrictive, she realised she 'couldn't live without it' as she experienced 'dehydration'. Her acceptance of having HPN at home was the motivation for her to cope with it the best she could.

- **Health with HPN (**Positive experiences)

'I don't feel as poorly. I'm feeling quite well and I look quite well. And everybody says I look quite well' (#1, p.3)

'If I come off it, I'll soon get dehydrated you see. I need to be on it' (#1, p.3)
'Well I won't be dehydrated will I? But it's still going to cause me more jaundice'' (#1, p.8). 'I won't have that' (#1, p.8)

'it's given me…it's made me feel better. I have to be on it, I know I got to be on it' (#1, P.14)

She 'felt and looked well' with HPN. She was pleased that her friends had noticed how well she looked since coming home with HPN. She was well informed of dehydration problems if she stopped HPN. She realised that 'she has to be on HPN'.

- **Independence** (Negative experience)

'Oh I don't know because I was very independent before' (#1, p.6)

'I mean I was, I always do me own work [house work].#' (#1, p.6)

'I used to work with people with learning difficulty……I worked, that was my job. I did that for ten years. And I used to being ….. no, I am not being used to be a patient, I'm a carer, not patient. I don't like it' (#1, p.6-7)

'I don't like people milling around them people. I like to do my own things……. I don't want to be fussing them and messing about round me. I like to do my own. But Keith puts me on it, I don't like it and I always think it's a bind and but I know I've got to be on it' (#1, p.7)

'Once you put these tpns on at night and you are pulling it around, you get fed up of doing it. I don't, I don't like it but I got to have it for my own benefits, I know that' (#1, p.13)

'I am used to being independent and all of a sudden I don't go out anywhere because I can't see that way, that is restricting me that way' (#1, p.13)

'Going out. Being able to go out, just taking off when you want. You know you have to just go out in the morning, stay out all day' (#1, p.13)
'I am just an independent person…. I'm just one of these that I want to go out, and go away and it's affected me probably more than them' (#1, P.14)

'All my friends are quite understanding and they, you know, they say 'I don't know how I'll cope If I were the same as you'. I just think, don't think I could cope' (#1, p.17)
'I can't carry shopping and I couldn't go on my own. I won't go down to Hillsborough or anywhere on my own because people are coming in front of you like this way and I don't see them' (#1, p.18)

'I mean I can put washing out, you know things like that, but I am careful when I do it but I'm a lot, a lot slower obviously than I were before but I do cope pretty good really' (#1, p.19)

She was resentful of the 'loss of independency' and 'loss of her job'. She disliked being 'fussed by others' and 'not being able to do her own thing'. But she realised that she could no longer manage everything by herself. She was grateful that she was 'being supported by' family members. She had 'gained independence' with simple house work and she did it at her own pace.

HPN Coping Strategies

Dimensions

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- **Choice**

'All I need to get this stoma done, get rid of stoma hopefully I can get rid of fluids' (#1, p.3)

'I don't like it, I'm restricted' (#1, p.3)

'So if I'm going out and I get back at half twelve, you've got to put the stuff on at half twelve, it's a bind' (#1, p.3)

'So what I've been doing on a Friday, I've been using that bag, carrier bag you know that bag on your shoulder that you carry, I've putting it in here and I've been carrying it when I gone to the pub, only a two hour thing, you know what I mean because it's not busy, and it's not like a Saturday night you know when it's not busy, and I can get away with it' (#1, p.3-4)

'at Friday night or Saturday night we go down to the Park Hotel and there is a lot more people, and it's a lot more noticeable and I don't feel comfortable putting this here' (#1, p.4)

'you feel more noticeable, and you've got the wire' (#1, P.4)

'you go to the toilet to empty stoma and you're carrying that to toilet, oh and then at night you got night bag on and then you got ~~tcp~~tpn stuff you know what I mean, you feel a bit.. you don't feel… you feel unattractive do you know what I mean, with all this on' (#1, p.4)

'I want to get the operation. And then I want to, if I can, I can then / I might get off fluids, if I get rid of stoma, I might get rid of the problem' (#1, p.9)

'I don't like it. I really don't like. I have to have it. ' (#1, P.14)

'it's not really their decision is it, it's mine' (#1, p.15)

'Yes, but you just got to, you just got to cope haven't you' (#1, p.17)

'I don't know, I think I got inner strength in me, must have' (#1, p.17)

'I mean you just adjust, don't you, you adjust to it, you got to adjust' (#1, p.19)

'I found it really overwhelming at first. But you do, you do adjust don't you. Like a routine isn't it, everything is like a routine' (#1, p.19)

She described the limitations on 'choice' in different aspects of her personal and social life. She felt the need to 'disguise' the Hickman line and the HPN bag when she went out as these made her felt 'unattractive'. She had to choose somewhere quite so that she felt less 'noticeable' by others. She was determined to socialise with close friends as 'a way of coping' with it.

- **Help**

'My husband puts me on it; I have to take myself off it. I do that because he puts it on at twelve and he has to click the bottom off and it's like a blue fastener, and I find it hard for me to take that off. So K always does that, and then he gets that wire, Hickman mm…….that line and he changes me Hickman line. All I do is take me of it' (#1, p.4)

'Oh they have been….they have been pretty good. Any where I want to go they don't have a problem' (#1, p.18)

P#1 suffered poor sight in one eye so she could not connect the administration set to the Hickman line and to operate the infusion pump safely. She needed help from her husband who set up the TPN feed to the infusion pump at night. He became the main carer for her and she's 'dependent' on him. She was 'being supported' by family members who would take her out where she want to go.

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Appendix 11a Theoretical Memo 3 open codes on stoma

10.10.2013

Open codes on stoma were collected concurrently from each interview transcript. The stoma was a common theme in subsequent transcript for participants #1, 3, 5, 7, 8 & 9. These codes were analysed concurrently using focus coding and they revealed information on the stoma and its impact on the participants' lives at home and in social situations. These excerpts and their open codes were tabulated in order to illustrate all the features associated with the stoma. I followed the method of axial coding described by Strauss and Corbin (1998 p.123) which supported the identification of the phenomenon stoma, its characteristics and corresponding properties. The same coding techniques were used to reveal information on the way these participants coped with stoma care at home and in social situations. The excerpts were underlined in order to reflect the open codes generated from the interview transcripts.

Open codes on stoma (#1, 3, 5, 7, 8 & 9)

Participant, page number	Excerpts	Codes
#1, p.1	And because the outcome of the stoma was such a great amount and …. ….I weren't keeping any fluids and you know what I mean…. …. they suggested that I go onto tpn (total parenteral nutrition, TPN), fluids at first and then overtime we're going to feed some fluids …. ….but I think it was the feeds that was somewhere along the line it's not actually suiting me because it's affecting my liver and Dr P had a word with me and he said that long term fluids are no good for me. I can only be on short term.	Watery contents & high volumes from stoma (negative experience) Malabsorption of fluids (negative experience) Realisation of need for tpn (negative experience) Long term side-effects from tpn (negative experience)
#1, p.2	Oh makes me tired, I can't walk upstairs and things like that and I'm really what's the word... really tired and not much appetite and literally makes me feel poorly and weak you know what I mean.	Feeling tired constantly (negative experience) Loss of appetite (negative experience) Feeling weak (negative experience)
#1, p.3	I started feeling tired and me back hurt you know what I mean that pain in the back that me kidneys so I was getting a little bit dehydrated…	Feeling unwell (negative experience) Dehydration (negative experience)
#1, p.10	I can have tinned spaghetti on toast, and I can be eating that and I can go to toilet and before I finish eating the spaghetti is down the toilet in stoma.	Malabsorption of food (negative experience) Disruption at meal times (negative experience)
#1, p.10	It passes out so fast the spaghetti, I don't know why. You know when I have gone to the toilet I actually saw what I am eating on the plate in the toilet at the same time.	Malabsorption of food (negative experience) Undigested food in stoma bag (negative experience)
#1, p.11	O god I can remember if I have something to eat, I can go to the toilet and empty this bag twenty times a day.	Lack of control with stoma frequency & volume (negative experience)
#1, p13	I can go to my daughter from my daughter to Meadow Hall, and I have to use toilets four times on the way there. It's a bind but it's the stoma that is a bind.	Frequent access to toilet facilities (negative experience) Frustration with frequent stoma losses (negative experience)
#1, p.16	I mean I don't want sexy nighties you know what I mean, but I would like something a bit more, a bit more …..	Lack of choice (negative experience) Unfulfilled desired

	what do they call them ….a bit more nicer you know what I mean.	(negative experience)
Participant, page number	**Excerpts**	**Codes**
#1, p.19	I always take my take my medications on time, take it with water. I don't need anybody taught me to do that.	Showing compliance in taking medicines (positive experience)
#3, p.3	They were very good and they would find you something but it wasn't a proper meal.	Poor alternative (negative experience)
#3, p.4	I wasn't absorbing enough and anything that would upset would make the output very watery and that wasn't a good thing.	Anxiety with watery stoma losses (negative experience)
#3, p.4	it was trying to keep it as, well, solid if I could but it was [the stoma output] never been more than slightly thicker and now and again it gets very wet and watery. So I have to be careful.	Confident with stoma care (positive experience)
#3, p4-5	I have the occasional leak or upset but the nurses were very good you know if you have trouble because if I did …it would … as it's very liquid, I'll be in a mess every time.	Embarrassment (negative experience)
#3, p.5	I knew I couldn't help it but I found it quite upsetting that somebody else has to clean you up and put things right because that was something I couldn't do at that time.	Upsetting (negative experience) Reliance on nurses (negative experience)
#3, p.5	No, I think I always felt the same when it happened. Even when I was at the Hallamshire [Royal Hallamshire Hospital], I found it still upsetting that I have to get assistance.	Upsetting (negative experience) Reliance on nurse (negative experience)
#3, p.7	it was worse as far as the stoma went because there was no stoma nurse there at the time.	Lack of support from nurse specialist (negative experience)
#3, p.7	I kept saying you know, 'is there another stoma nurse about?' 'Oh, she'll get to you' – well she didn't until I was probably a week before I came out.	Needing nursing help (negative experience)
#3, p.8	I saw the stoma nurse and she changed me the whole system which was so much better. I couldn't understand why they hadn't put me on that before. So much easier and so much better.	Satisfaction with nurses' advice (positive experience)
#3, p.8	that was a complaint but nobody had seen me before said that there was this other system – I had no idea there was another way attaching the bags.	Lack of information (negative experience)
#3, p.8	It's all quite complicated to start with. I mean once you have been doing it for a while it becomes easier but still quite, quite a long process.	Confident with stoma care (positive experience)
#3, p.9	Well again, if I have to, I have to and this was it. You know just get on with it.	Acceptance own situations (positive experience)
#3, p.9	If you don't (laughter), there is no answer to it if you don't accept that and you might as well not bother.	Acceptance own situations (positive experience)
#3, p.9	It was hard to think that I have to do all this on my own you know because I live alone.	Loneliness (negative experience)

#3, p.9	there again I mean you just get on with it.	Accepting own situations (positive experience)
#3, p.9	It took me a day perhaps to think 'well *you've got to get on with it and that's it*'. So it didn't really upset me.	Accepting own situations (positive experience)
Participant, page number	**Excerpts**	**Codes**
#5. p.8	I am constantly tired from getting up and out of bed four, five, six sometimes more times to go to the toilet. And then you just get to a stage when you are that tired as soon as your head hits the pillow you're out.	Feeling tired constantly (negative experience) Disrupted sleep (negative experience)
#5, p.8	I do get up to go to the toilet four, five may be six times at night depending on what I have to eat through the day.	Disrupted sleep (Negative experience)
#5, p.8	I'm always tired because I'm having broken sleep most nights so I just don't go anywhere.	Feeling tired constantly (negative experience) Disrupted sleep (negative experience) Loss of social life (negative experience) Becoming house-bound (negative experience)
#5, p.14	I don't..I have…everything basically everything I eat go straight through anyway but I notice with cheese and fruits that (laugh)…down the toilet straight away.	Malabsorption of food (negative experience) Undigested food (negative experience)
#5, p.14	Really because you don't know what's going to happen to you, don't how you are going to react to it if I need to go to the toilet and you can't get to one quickly. And if you can't get a toilet quickly, you're going to be embarrassed and you have to come home, get changed, get showered… …..so it's…..basically I am house-bound.	Anxious with access to toilet facilities (negative experience) Embarrassment with leaks (negative experience) Loss of social life (negative experience) Being house-bound (negative experience)
#5, p.6	…..the amount of time I went to the toilet, talking twenty plus times a day just to the toilet which sometimes you don't actually make it up the stairs…because you just can't stop yourself.	Troublesome uncontrolled chronic diarrhoea (negative experience)
#5, p.8	I am constantly tired from getting up and out of bed four, five, six sometimes more times to go to the toilet.	Disrupted sleep (negative experience) Feeling tired constantly (negative experience)
#5, p.8	I do get up to go to the toilet four, five may be six times at night depending on what I have to eat through the day.	Uncontrolled chronic diarrhoea (negative experience)
#5, p.14	I don't..I have…everything basically everything I eat go straight through anyway but I notice with cheese and fruits that (laugh)…down the toilet straight away.	Malabsorption of food (negative experience)
#5, p.14	It's one of the reasons why I don't go out like I used to because if it happens when I'm out, what do I do? I have to turn round and come straight back home. I'll be embarrassed sat in somewhere busy; it's just a no no.	Loss of social life (negative experience) Anxious with access to toilet facilities (negative experience)
#5. P.6	…..the amount of time I went to the toilet, talking twenty plus times a day just to the toilet which sometimes you don't actually make it up the stairs…because you just can't stop yourself.	Uncontrolled chronic diarrhoea (negative experience) Embarrassment with accidents

		(negative experience)
#5, p.14	Really because you don't know what's going to happen to you, don't how you are going to react to it if I need to go to the toilet and you can't get to one quickly.	Anxious with access to toilet facilities (negative experience)
#7, p.4	I still find it difficult, I find it stings a lot, I find it itches a lot and….	Discomfort at stoma site (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.5-6	the stoma fills up very quickly and you can see, you can see it bulging out and then I feel conscious that it's getting heavy so I have to rush upstairs to go to the toilet.	Self-conscious with stoma bag (negative experience) Anxious to empty stoma bag (negative experience)
#7, p.6	I have been in a situation where it has leaked and you can just sense that tickling feeling and I just have to leave everything and rush off to the toilet.	Trying to minimise leaks (negative experience)
#7, p.9	Yes, again I think that was the nurses that explained that why I had the stoma and that I wouldn't absorb enough food. I wouldn't absorb the calories that I needed or the nutrients that I needed, and therefore, I needed to be on the tpn for quite some time…	Malabsorption of food (negative experience) Dependent on tpn at home (negative experience)
#8, p.2	Anything I take in, it comes straight out into a stoma bag….	Undigested food (negative experience)
#8, p.2	Everything that goes in, more or less comes straight out.	Undigested food (negative experience)
#8, p.16	If I have a drink it comes straight into my bag [stoma]. If I don't empty it, the bag pulls away….it gets heavy, it holds about 300ml and when it gets full, it's heavy so it pulls away from the skin and then that leaks.	Malabsorption of fluids (negative experience) Frequent emptying of stoma bag (positive experience) Confident with stoma care (positive experience)
#9, p.1	I wasn't getting any nutrition through the food I was eating.	Malabsorption of food (negative experience)
#9, p.6	two or three times it has leaked and I put a bag on it and it leaked through…. At half past seven I woke up and it's just started to leak through the bottom of the bag and that is the problem.	Unpredictable leaks (negative experience) Troubled by leaks (negative experience)
#6, p.6	it's definitely a bind and a worry it's going to leak in an opportune moment.	Worried about leaks (negative experience)
#9, p.16	when the bag's blown up or it's filling up it must be emptied, that brings me back down to earth for a few minutes.	Anxious about leaks (negative experience)
#9, p.17	What you got nutrition from is the tpn obviously. This is what I've accepted ….	Dependent on tpn at home (negative experience)

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Participant, page number	Excerpts	Codes
#1, p.4	when you go out, I have to wear dark cloths in case stoma goes. If I am wearing something like pale blue and stoma goes it's just going to come through. I'm always concerned about bag leak.	Lack of choice with clothes (negative experience) Dark colours to disguise leaks (positive experience) Anxious with leaks (negative experience)
#1, p.5	Yeah, like Imodium but it's not called Imodium. Three of them, no, four of them, six of them four times a day. To slow stoma down a little bit.	Taking medicines to reduce losses (positive experience)
#1, p.5	I have to have them (Loperamide) in powder so I take them in water, I have six of them four times a day and two codeine four times a day.	Taking medicines to reduce losses (positive experience) Compliant with instructions to take medicine to reduce losses (positive experience)
#1, p.6	Oh I don't know because I was very independent before.	Loss of independence (negative experience)
#1, p.6-7 #1, p.7	I used to work with people with learning difficulty……I worked, that was my job. I did that for ten years. And I used to being ….. no, *I am not being used to be a patient, I'm a carer, not patient. I don't like it*.	Loss of job (negative experience) Loss of independence (negative experience) Unhappy as a 'patient' (negative experience)
#1, p.10	When I am going out to things like that, I am always a little bit unsure about the stoma, do you know what I mean, it's either come off or fallen out.	Anxious with stoma bag falling off (negative experience)
#1, p.11	I have to pick what clothes to wear so I have dark clothes on when I'm going out.	Lack of choice (negative experience) Wearing dark colours (negative experience)
#1, p11	Sometimes if you are travelling you have to sit in front so you can stretch your legs so you are not cramped up because if you sit cramped, it comes off sometimes, the bag.	Resourceful (positive experience) Preferring the front seat when travelling by car (positive experience)
#1, p11-12	You have to be careful what to wear, be careful where you go because I need toilets. I want to go somewhere with a lot of toilets.	Resourceful (positive experience) Preferring to go to places with easy access to toilet facilities (positive experience)
#1, p12	I'm thinking is it going to flush toilet, do you know what I mean. And it's always things in your mind, '*I hope it's going to flush this toilet before I go out*'.	Anxious when using public toilets (negative experience)
#1, p12	I've used the toilets there and they haven't flushed. It's awful and I don't like it.	Embarrassment (negative experience)

	I find it right degrading.	Feeling degraded (negative experience)
Participant, page number	**Excerpts**	**Codes**
#1, p16	I'm so restricted ……. plan around stoma and ….you empty stoma and then at eight o'clock you go to bed with tpn and stoma, and then when you get in bed you got night bag on and you got stoma and you got Hickman line – I don't……it's not very…….I probably think I'm a lot younger than I am you know.	Restriction with mobility (negative experience) (negative experience) Poor self-image (negative experience)
#1, p16	I mean I don't want sexy nighties you know what I mean, but I would like something a bit more, a bit more ….. what do they call them ….a bit more nicer you know what I mean.	Lack of choice (negative experience) Dissatisfaction with self-image (negative experience)
#3, p3	Now the diet is very limiting.	Dietary restrictions (negative experience)
#3, p3	sometimes there is nothing that I can select that I could have so they would perhaps find me a sandwich.	Lack of choice (negative experience)
#3, p3	I think probably after about ten days. Somebody came and explained that it would be, I wouldn't be able to eat vegs or fruits and only certain ones and I should eat little and often which you can't do in hospital.	Dietary restriction (negative experience) Limited choices (negative experience)
#3, p4	I will be on limited liquids, I can only have 1500cc a day and I found that difficult.	Feeling forced (negative experience) Restrictions with oral fluids (negative experience) Struggling to cope (negative experience)
#3, p.4	I was used to drinking a lot and then suddenly I can only have a cup of coffee perhaps at breakfast and little sips in between and a drink at lunchtime but not with lunch and that was another awkward thing I have to wait half an hour after eating to have a drink.	Restrictions with oral fluids (negative experience) Strict dietary regimen (negative experience)
#3, p5	I found that upsetting.	Upsetting (negative experience)
#3, p5	I knew I couldn't help it but I found it quite upsetting that somebody else has to clean you up and put things right because that was something I couldn't do at that time.	Upsetting (negative experience)
#3, p.5	I very rarely get a leak, I mean now and again obviously you do but I know immediately and I just go and change and clear up.	Confident with stoma care (positive experience)

#3, p.5	I can manage what is happening now.	Confident with stoma care (positive experience)
#3, p.5	Not really well prepared.	Lack of information (negative experience)
#3, p.5	I don't think you can be for something like that (long pause)	Unexpected (negative experience)

Participant, page number	Excerpts	Codes
#3, p.5-6	I don't think anybody explained how you would feel and how it would be but…. …. that is something that you learn anyway. You understand it could happen.	Lack of information (negative experience) Unprepared (negative experience) Learning to cope (negative experience)
#3, p.6	No, I don't think so really. I think it's something you learn yourself.	Self-discovery (positive experience)
#3, p.6	No, I just coped with it.	Determination to cope (positive experience)
#3, p.7	I was finding it very difficult then to cope with the stoma because I felt so ill.	Too ill to cope (negative experience)
#3, p.7	I did manage but they were times when I'll forget to put stopper in or you know and then…. ….you feel awful because it was your fault that you've made such a mess.	Forgetful (negative experience) Frustration (negative experience) Embarrassment (negative experience)
#3, p.8	It's all quite complicated to start with. I mean once you have been doing it for a while it becomes easier but still quite, quite a long process.	Learning stoma care (positive experience) Becoming confident (positive experience)
#3, p.8	Well I just knew I have to so… …. I was a bit slow probably in learning but at eighty-three you think, well I can be excused (laughter).	Feeing forced (negative experience) Lack of choice (negative experience) Acceptance (positive experience) Humour (positive experience)
#3, p.12	I can cope with the stoma but there's nothing I can do about the tpn. I've got to be here [at home] to do it.	Lack of choice (negative experience) Dependent on HPN at home (negative experience)
#3, p.12	..with the stoma I can manage it if I'm out for a couple of hours and I need to empty the bag I can cope with that now so I can go out for longer.	Confident with stoma care (positive experience) Social mobility (positive experience)
#3, p.12-13	Once I wasn't going out for long because as soon as it starts to fill, I want to be home to empty [the stoma]… ….but now I can cope when I'm out.	Feeling anxious & worried (negative experience) Becoming confident (positive experience)

#3, p.13	So I'm not quite as limited as I was. It's taken quite a long time to get the confidence to do that.	Becoming confident (positive experience)
#3, p.13	at first I didn't want to empty the [stoma] bag anywhere but here even at my daughter's house I didn't want to.	Unfamiliar environment (negative experience) Feeling uneasy (negative experience)
#3, p.13	I just felt more comfortable doing it [the stoma bag] here in case my make a mess probably which I could cope with here but couldn't when I was out. But now I know I'm fine you know.	Unfamiliar environment (negative experience) Becoming confident (negative experience)
Participant, page number	**Excerpts**	**Codes**
#3, p.13	I probably only been emptying it [the stoma bag] elsewhere this last six weeks. Takes me a long time.	Overcoming anxiety (positive experience) Becoming confident (positive experience)
#3, p.13	I did have a stoma nurse who called here as soon as I came home and she was very helpful… I can ring if I need her, I can ring….so that I feel I have back up there.	Needing reassurance (positive experience) Becoming confident (positive experience)
#3, p.15	I mean I got the carers, I got the stoma nurse coming in, and I got the Willow nurse in the evenings so really I think I've got all that I needed.	Reassured (positive experience) Becoming confident (positive experience)
#3, p.15-16	…. when I first came home it was difficult, I mean my daughter came for the first couple of days but she wasn't well herself so it was very difficult. I know that when I was in hospital she was ill so that was worrying.	Realisation (negative experience)
#3, p.17	I'm on Loperamide and I take three [tablets] four time a day	Compliant with medicines (positive experience)
#3, p.17	when I was really ill, I felt it [Loperamide] was that that was not helping me at all and I stopped taking them altogether.	Lack of understanding with how medicine works (negative experience)
#3, p.17	when I was coming out they did ask me to take them again so I do take them and they did put it up last time.	Accepting doctor's advice without questions (positive experience)
#3, p.17	It's to thicken the output…the Loperamide.	Finding benefits from medicine (positive experience)
#3, p.17	I have to powder them [Loperamide capsules] which are very difficult when your hands are getting on (laughs).	Having problems to open the gelatine capsules (negative experience)
#3, p.17	When I take it [Loperamide] in some Bitter Lemon usually, just a tiny drop of Bitter Lemon and I don't notice the very bitter taste. It's easy to take really, you just gulp it down, have a sip of something else afterwards	Resourceful (positive experience) Disguising medicine taste (positive experience)

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	(laughs).	
#5, p.2-3	No I haven't spoken to anyone. It's something I've got to…it's something I've got for the rest of my life. It's something I've got to get on with and stop mopping around basically.	Not disclosing own feelings to others (negative experience) Accepting own situations (positive experience) Refusing self-pity (positive experience)
#5, p.3	I want normality back in my life which is really hard with this amount of time that you go to the toilet.	Loss of normality (negative experience) Frustration (negative experience)
#5, p. 3	So basically if you want to go anywhere, don't eat anything even though your stomach still makes a certain amount of acids..	Resourceful (positive experience) Avoiding fluids or food (negative experience)
Participant, page number	**Excerpts**	**Codes**
#5. P.3	….but you can manage once or twice whilst you're out but when you start going [to the toilet] three, four, five times an hour, it gets a bit much so if you go anywhere, just don't eat anything.	Avoiding fluids or food (negative experience) Accepting restrictions (negative experience)
#5, p.3-4	I bagged and pleaded with the doctors to allow me to return to work. At the end of March I went back to work and I think I was possibly two and half to three weeks. My boss looked at me one day and he just said, 'You clothes off, work wear off, get dressed, get yourself home'. He said, 'You look shocking'.	Wanting to keep employment (positive experience) Being told unfit to continue work (negative experience)
#5, p.4	*Tremendous stress* with all that in my own surroundings…and that feeling, knowing I'm at home, I'm on the mend but it was…I don't know how to explain it… …but it was a really good feeling to be at home even though …I was still in a mess.	Tremendous stress to cope alone (negative experience) Feeling good at home (positive experience) Realisation of own situation (negative experience)
#5, p.6	A typical day would be…..getting up, washed, toilet…changing the stoma bag or emptying the stoma bag which I used to do two to three times in the night.	Living independently (positive experience) Confident with stoma care (positive experience)
#5, p.6	Then breakfast either toast or a few cornflakes which I stop taking now because it's a no no and it makes me going to the toilet more often.	Following dietary restrictions (positive experience) Reducing high losses (positive experience)
#5, p.6	You then need a shower, clean clothes and I don't want this happening when I'm out. So I don't go anywhere. It's a real, real bug bear for me.	Fear of accidents in public places (negative experience) Becoming house-bound (negative experience)
#5, p.6	My niece or my brother… they do a hell of a lot for me and my big sister. ……my niece who is a district nurse – she did a hell of a lot because she was really concerned….	Dependent on help from family members (positive experience) Awareness of concern from relatives (positive experience)

	…….but I do actually do a lot of it myself now even though I get tired real quick.	Able to self-care (positive experience) Feeling tired (negative experience)
#5, p.6	I just hover around and that's it, I'm drained, no energy. I have always been used to working hard and not having the energy just to do cleaning up…*I was shattered*.	Feeling tired (negative experience) Lack of energy (negative experience Feeling shattered (negative experience)
#5, p.7	I am always tired, always tired and constantly cold. I don't know whether it's anything to do with my medical condition.	Feeling tired & cold (negative experience)
#5, p.7	I've lost half of my stomach….and they say the warmest part of your body is your stomach. I don't know but I am constantly cold and constantly have the central heating on which is stupid money.	Realisation of poor health (negative experience) Financial burden (negative experience)
Participant, page number	**Excerpts**	**Codes**
#5, p.7	It is better now because I've basically…I got used to it.	Accepting own situations (positive experience)
#5, p.8	I do get up to go to the toilet four, five may be six times at night depending on what I have to eat through the day.	Disrupted sleep (negative experience) Uncontrolled diarrhoea frequency (negative experience)
#5, p.8	I'm always tired because I'm having broken sleep most nights so I just don't go anywhere.	Feeling tired constantly (negative experience) Disrupted sleep (negative experience) House-bound (negative experience) Social isolation (negative experience)
#5, p.8	By having cat-naps sleeping in afternoons....a lot of the times I have a sleep on the settee.	Having cat-naps (positive experience)
#5, p.8	Other than that I hardly go anywhere because of my medical condition.	Loss of social life (negative experience)
#5, p.12	I take Loperamide. I take eight 2mg tablets four times a day. I take Codeine Phosphate one [tablet] four times a day, I think it's 60mg. I take Omeprazole two [tablets] twice a day and Paracetamol for pain. And loads and loads of Germaloid that I have to buy over the counter because the amount of times I went to the toilet, my back passage is constantly sore, constantly swollen.	Understanding medication regimens (positive experience)
#5, p.13	I did get to see the dietitian but he never told me what I could and couldn't eat. It's one of those things where I'm having to find out	Lack of information (from dietitian) (negative experience) Resourceful (positive experience)

	myself by having various meals what I used to have before the accident and finding out how…how my bowel puts up with it.	Managing dietary restrictions (positive experience)
#5, p.13	Most of curries are a no no, cereals are a no no, and fruits are a no no and that's what I've found up to now.	Resourceful (positive experience) Learning from trial-and-error (positive experience)
#5, p.13	I still eat fruit because I used to eat loads of fruits before the accident. I still have it now if I am feeling…sod the consequences sod the toilet, I'll have some fruit and I'll have an orange, an apple or a pear…	Satisfying own desires (positive experience) Making choices (positive experience)
#5, p.13	…..but it's only one every couple of days and I thought sod the consequences because I know it's going to make me go to the toilet but so is a curry. I'll have one may be once a fortnight, once a month and sod the consequences.	Making choices (positive experience) Satisfying own desires (positive experience)
#5.p.13	I can't do with not eating meals that I like just because it makes me go to toilet. I put up with it because I like what I eat.	Refusing to compromise (negative experience) Satisfying own desires (positive experience)
Participant, page number	**Excerpts**	**Codes**
#5, p.13	I've always been a good eater and I ate anything that is put in front of me. And now I have to be careful what I do eat which is horrible…cheese, cheese is a no no, I don't know why but cheese makes me go to the toilet.	Dietary restrictions (with dietary restrictions) Having to change eating habits (negative experience)
#5, p.13-14	Probably because they don't know what I used to eat and what I can eat now. It's…I can't say it's their fault. I got to say they don't know what I like to eat, they don't know how my bowels will react to what I eat. It's a thing I have to find out for myself how my bowels are going to react what I eat.	Lack of information (negative experience) Dietary restrictions (positive experience) Learning from trial-and-error (positive experience)
#5, p.14	Only if it's in their house. I don't go if they are in a pub or anything like that because I know if I'm in a pub I've got to have a drink. Compare to what I used to drink, I hardly ever touch the stuff now.	No alcoholic drinks (negative experience)
#5, p.14	So if it's a partly, it's usually my niece's little boy's birthday and I would not stay long because they've got their own lives to lead and they have their own friends, very close friends and their own kids - too many kids for me (laugh), screaming kids.	Making effort to maintain social contacts (positive experience)
#5, p.16	No, not at all. I don't' know why. I've looked on the internet, different things but nothing really appeals to me. I don't think I could cope with being in the same room with people with the same predicament because I would be like, what do you say to them? I would not know how to speak to somebody else who's got the same as me on HPN. I wouldn't know what to say.	Lack of interest with self-help groups (negative experience) Not disclosing own feelings to others (negative experience) Loss of confidence (negative experience)

#5, p.16	Sometimes it gets me depressed like now [laugh] when you talk about it, it's depressing.	Depressed with own situations (negative experience)
#7, p.4	And even to the point when I had the training [with stoma care], I mean when it was changed by the nurses, I couldn't even bear to look at it [stoma], I just find it hideous. But when the stoma nurse said that I have to start doing it myself and came to give me some training, and I found it really difficult…. but she was so lovely, she was so patient and I could remember the first time I did it I was pulling faces and she said at the end, 'We did well there', and she said, 'We would do it again tomorrow but we would pull less faces when we do it'. She was really, really good, she was very patient, she was very kind, she was very understanding. And I suppose now I just do, you know I change it and you do get used to it but….	Not accepting stoma (negative experience) Reluctant to learn (negative experience) Accepted encouragement from stoma care nurse (positive experience) Appreciated kindness, understanding & patience from stoma care nurse (positive experience) Confident with stoma care (positive experience)
#7, p.4	it has an impact when I'm out on my social life.	Impact on social life by stoma (negative experience)
#7, p.5	I think it was the difficulties that I have were I was thinking that everyone would know that I have actually got a stoma.	Self-conscious & desire to hide stoma (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.5	Lots of nurses were really kind and they were saying that lots of people have stomas and you don't know who they are and you have no idea that someone here has one [stoma]. We won't say who it is but you don't know that so no one would know unless you tell them. Which…which made me feel more confident….	Kindness & reassurance for nurses (positive experience) Confident with stoma care (positive experience)
#7, p.6	There is a café that we go to and I daren't leave that place for about half an hour after I have finished because I know I'm going to be up and down, up and down because if I actually leave the place and walk off and the shop closes and I will have to jump into a taxi and get home.	Anxious to empty stoma (negative experience)
#7, p.6	So I need to be safe, I need to feel I am in somewhere where there are plenty of toilets and I'm not going to queue and I'm not too far away from toilets so…. I have a list in my head now of shops that I know at times they close and I can go and use them [the toilets]. So although the nurses were good in that respect no one would know. When you are out with a bunch of people even if they don't know I think they will know by the time you finished running about. I went out for my friend's birthday last week and there is this sense of where the toilet is once you are in there, having my bag around me, every time I go to the loo I	Easy access to toilet facilities (negative experience) Anxiety with unfamiliar places (negative experience) Resourceful (positive experience) Access to toilets facilities (negative experience) Anxious to disguise stoma (negative experience) Anxious to know where toilets were (negative experience)

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	have to take my bag with me just in case because…. And I didn't know where the loos were at that point, so I was in a real flap, I was really anxious I thought this is just going to go everywhere. So now I always make the point of knowing where the toilets are as soon as I go in somewhere so I can sit with one eye on the toilet door.	 Anxiety with leaks (negative experience) Looking out for toilets (positive experience)
#7, p.7	I think it was towards the end of my stay in hospital when I was having the support from the stoma nurse and she would come into the loo with me and then any little problems or if I was wondering about what if that happens she would put my mind at rest. And then eventually I was left to my own device, they would pop in and just say how are things, I'll come tomorrow and we'll have a look and see how it looks and how things are. *I don't think I have fully accepted it now*.	Support & reassurance from stoma care nurse (positive experience) Confident with stoma care (positive experience) Not accepting stoma (negative experience)
#7, p.7	I can remember just before I came out of hospital I was, I think someone has said to me, 'Have you thought about what would happen if you can't have the reversal and you have to have this for life?' I just couldn't bear the thought of that… [P7 started to cry again], I was really upset and one of the male nurses came in and closed the curtains and sat with me for about half an hour and had a chat about it.	Upset with permanency of stoma (negative experience) Comfort from nurses (positive experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.7	But no, I still don't think I have properly accepted it [the stoma]. I just felt it had such an impact on my life and it's something that is around constantly.	Not accepting stoma (negative experience) Life-changing impact (negative experience) Being a constant reminder (negative experience)
#7, p.7	I didn't. I got a stoma nurse who she delivers the stuff. She's really nice and she's really down to earth and when she comes she'll spend an hour in here and have a chat about this that and other. She's really supportive and I don't know, I don't think I really wanted to be part of a support group. There was someone who's sharing my bay in the hospital and she said she has a friend, a male friend who had a stoma for eighteen years. And I think I was complaining for a couple of days that it was bleeding a bit because that still happens, I think it just catches round the edges sometimes. It really stinks and I've seen there is blood in the bag and she said if you want when he rings I'll let you have a word with him. So it was interesting and I asked how he coped with it and he said he coped fine but even then it didn't make	Kindness & support from nurse (positive experience) Dislike for support group (negative experience) Accepting advice from another patient (positive experience) Being reminded of own situations (negative experience)
7-8		

8	me feel any better because I don't know what his circumstances were and for me, my life is still affected in a way that it hurts. So whatever his experience was, although he said that's normal, that's' normal, yes it will sometimes stink, yes it does itch like mad, you just got to put up with it. He didn't really make me feel any better.	Bad smell from stoma (negative experience) Discomfort at stoma site (negative experience) Feeling upset with own situations (negative experience)
#7, p.8	I think I'm probably putting my head in the sand a little bit and thinking I don't want it to be something that's long term and…. therefore I don't want to be part of a support group because I don't want to think that this is my life from now on. And that's me I'm just seeing it as something that I got to put up with until I have the next operation.	Not accepting own situations (negative experience) Association of self-help group with permanency of own illness (negative experience) Choosing to believe illness as short-term condition (positive experience)
#7, p.15	Tired, very, very exhausted and still in pain. I was struggling to get off the sofa, struggling to get out of bed which I still do in the morning, it still pulls [P7 was pointing at the stoma site and the abdominal wound], it's still painful because there is still an open wound there – it has not healed properly yet. Thinking that I could do things and then realised how tiring it was.	Tiredness & poor pain control (negative experience) Reduced physical mobility due to pain (negative experience) Realisation of own situations (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.16	Just little things like washing my hair as well, knowing that I couldn't bend over. I felt really tired from just washing my hair. I felt my legs were not going to hold me any longer, and then I get really hot and bothered. I was sweating because I felt like I was almost shaking trying to keep myself standing. I would nod off easily as well if I sat on the sofa in the afternoon. In fact I can do that now. It would get to a certain time and I just think gosh such a feeling of tiredness over-helms me, my eyes close and I'm out like a light.	Loss of physical strength to self-care (negative experience) Tiredness from washing hair (negative experience) Felt unwell with attempts to self-care (negative experience) Chronic tiredness (negative experience)
#7, p.16	And I think sometimes I'm finding it easier to sleep in the afternoon, one because I'm so tired, two when you go to bed when you got the stoma and you got the HPN as well, your sleep is disturbed so much you are either going to empty the stoma or I think I've got to go and empty it I'm so conscious of it leaking that every time it's filling up a little bit I must go or the HPN makes you want to go to the toilet.	Disrupted sleep (negative experience) Anxiety with leaks from stoma at night (negative experience)

	So particularly on HPN night, it's like a double whammy – it's not just the stoma, it's the HPN as well.	Struggled to cope with tpn and stoma on the same night. (negative experience)
#7, p.16	So I do tend to feel really exhausted in the morning so I sit down and end up nodding off.	Tiredness from disrupted sleep (negative experience) Nodding off from tiredness (negative experience)
#7, p.16	I wasn't doing any shopping initially. My partner was doing it.	Dependent on help from partner (negative experience)
	I was finding it tiring just to walk up to the top of the street.	Loss of physical strength (negative experience)
16-17	I was trying to get out and do a little bit of walking but it was really tiring so I couldn't carry anything and I wasn't really doing any house work.	Loss of physical strength (negative experience)
17	And then after a couple of weeks I started doing a little bit of dusting because it's something I could do standing up and it wasn't heavy even though my partner was telling me not to do that either.	Gaining physical strength (positive experience)
	He [P7's partner] just wants me to sit down, to rest and relax but I thought at least I feel useful if I am doing something.	Felt positive with own situations (positive experience)
	And then gradually I think we kept building up and kept building up little walks and just building my strength up basically. And then through time, I think it was a long time though, that you realised you have managed to wash to your hair and you weren't ready to sink on your knees that….	Realisation of physical improvement (positive experience)
	I wasn't that tired as I had been because I can remember once going into the back bedroom and I bent down to pick something up and I just felt like my knees weren't going to hold me so I had to fall down onto my knees, and then I couldn't get back up off the floor.	Bad memories of feeling too weak to self-care (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.17	I didn't have the strength to get back up again, so it was coming to terms with what I thought I could do what physically I was capable of and then realising that actually I wasn't physically capable of doing it.	Realisation & acceptance of own situations (negative experience)
	But one day you realise you have done something and you are not having to think about it which is fantastic.	Surprised with physical improvement (positive experience)
#7, p.19	So you do feel like you are on the outside again….that you can't continue with the activity that you were doing before so it does make you feel a little separated and I think it's coming to terms with that.	Social exclusion (negative experience) Awareness of own situations (positive experience)
#7, p.20	She said in fact it frightens me you have been in here now; the risk of infection is so high because of the steam and the water and everything.	Exclusion from social setting (health spa) (negative experience)

	She said you have been working too hard, you tried to put weight on when you are on HPN, what is the point of coming and burning more calories; you're going to have to eat even more. She said you are just on a vicious cycle then. So she said I think what you need to do is go away, chill out, put some weight on and you have the operation over with, you can come back and we'll keep it suspended.	Loss of own desires (negative experience)
	This was really good but I remember walking out feeling so despondent because part of me thought [P7 was feeling tearful at this point]…	Loss of own desires (negative experience)
	….that was one thing I enjoy doing, it was a bi g part of my life and it really cheers me up. Now I can't do that.	Loss of own desires (negative experience)
	So I thought I'll start walking which I have done and we do a lot of walking before anyway but sometimes I will even walk to my appointments at the Hallamhsire, and I'll go via Weston Park.	Attempts to improve physical fitness (positive experience)
#7, p.21	Being a vegetarian for over thirty years, I found that when I was doing my weights they were anything between 50 and 53kg so there is not stability, it was not consistent – it was up, it was down….	
	….so I make the big decision to start eating meat in March – it's not what I wanted to do but I thought I'll give it a try.	Change of eating habits (negative experience)
	my partner has been nagging me even last year in hospital. He kept saying, 'I think it would do you good to build some muscles up'.	
	And I said, '*I can't bear the thought of it and I haven't eaten meat since I was thirteen and there is no way I can go back to eating meat*'.	Feeling forced to change eating habit (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.22	But I was getting so frustrated with the weights and I knew that if I put weight on then there is a chance that one of the nights can come off for the HPN. And I thought they are never going to take anything off it if I'm going up and down like this.	Frustration with weight loss (negative experience) Changing eating habit to gain weight and reduce HPN nights (positive experience)
#7, p.22	So I think it was March, the beginning of March, I started eating meat again…	Change of eating habit (positive experience)
	….and I saw such a rapid difference because it doesn't go through the system as quickly….	Stoma output less frequent (positive experience)
	…. it takes a lot longer it's almost like it can go overnight before you start seeing what you know is the meat coming out and it's completely dissolved - there are no	Stoma output less watery (positive experience)

	bits or anything. But with the meat it has really slowed it down and since then my weight has progressively gone up and up and up, and I got weighed last Friday, I was 56.1kg.	Reduced stoma output from change of eating habit (positive experience) Weight gain from change of diet (positive experience)
#7, p.22	I was over the moon. I phoned A [P7's partner] at work to tell him so it's gone from 50, 51, 50, 53 and then each week you can just see it go up and up. From March to middle May so I was, I couldn't believe it.	Happy with weight gain (positive experience)
#7, p.22 -23	So although it was difficult, I have actually got into it now.	Satisfying own desires (negative experience)
#7, p.22 -23	I saw a new world of recipes so I feel like …at least there is something I got some control over and… …. I couldn't believe what a difference it's made and that's the heaviest weight I have since I was in hospital.	Having control over diet (positive experience) Pleased with self-image (positive experience)
#7, p.24	I was given a booklet and it looks like a standard Sheffield Teaching Hospital booklet and it has foods that are not high in fibres. I have found it quite restrictive, I know I have to eat more fat and things and there is a lot of sugary things as well. I'm not a sweet person and I don't want to start eating it. I know there are other things that be caused by eating too many sweets.	Special dietary information (positive experience) Limited food choices (negative experience) Dislike for sugary foods (negative experience)
#7, p. 24	And that was one of the reasons also that I started eating meat because there is such a lack of vegetables on there and I think it was carrots, potatoes and swedes and something else but they are mainly winter vegetables.	Change of eating habit (negative experience) Limited food choices (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.24	So I did find it very, very restrictive and I was told that all I could do really is try some of the things and see what the effect would be.	Trial & error with food choices (negative experience)
#7, p.25	But I went on the Internet and I was looking at what other health authorities have said….	Resourceful in seeking information on food choices (positive

	…. and I found a very similar booklet – it looked almost identical in format for I think it was a South Devon PCT and the foods on there were low residue foods and were far more varied, the vegetables were far more varied including things like sweet potatoes, squash, bean shoots.	experience) Discovery of more choices for low residue foods (positive experience)
#7, p.26	I sorted of tried it because I thought it made sense because beetroot I thought was not green vegetable, it's like carrot so I've been eating sweet potatoes now having them roasted in the oven. I've had squash, I've had beetroot and I've been fine with them and it made such a difference to be able to have something else …. …. because if you are restricted to potatoes, and I do like potatoes and carrots are fine but they don't go with everything and then swedes and parsnips are winter vegetables. What do you do now when they are not in season?	Trial & error with food choices (positive experience) Enjoying different vegetables (positive experience) Struggling with restricted food choices (negative experience)
#7, p.26	Not that I particularly went out that much, it's just that now there is so much thought have to go into it…. ….there is so much more anxiety around social situations. What am I actually selecting to eat? When we are actually eating? What I can do, is it a HPN night?	Lack of choice on where to go (negative experience) Anxiety in social situations (negative experience) Making compromises with HPN and stoma care routine (negative experience)
#7, p.26 #7, p.26 #7, p.27	*I do feel it has totally changed my life but not for the better obviously*. I do feel I'm missing out on things and I know I could have had the opportunity to go to Greece with A [P7's partner] …. And I know how things are in Greece; people eat out a lot later so that would interfere with being able to have the HPN. It would mean A would be going out by himself and I would be staying in the flat by myself. So in the end it was easier just to say go by yourself and I'll stay here. Yes, I do feel I have lost out.	Realisation of own situations (negative experience) Loss of own desires (negative experience) Loss of choice (negative experience) Finding the HPN regimen restrictive (negative experience) Loss of social life (negative experience) Loss of enjoyment in life (negative experience)
Participant,	**Excerpts**	**Codes**

page number		
#8, p.7	Well I do eat – not that it does anything (laughs).	Using humour to disguise malabsorption of food and fluids (positive experience)
#8, p.7-8	The doctors at Sheffield decided that I needed to eat something just for social aspects. When we do go out or we have dinner at home that I am participating in the meal or the social aspect.	Accepting advice to eat for social reasons (positive experience)
#8, p.8	I take the Loperamide….to be honest I think I am supposed to take it before food or after food but I actually take it first thing in the morning and lunch time, tea time and then at night before I go to bed. Before I was taking it four times a day….to be honest I don't think it does anything any way. Because I've not got a proper stoma and what I have to do with the capsules…I have to break them up and I have to put them [the powder] in water and I have to take it that way. So when I drink it, it comes straight out any way [laughs]…	Choosing not to follow advice on taking oral medication (negative experience) Lack of effect from oral medication (negative experience) Using humour to disguise disappointment with failure to absorb an oral medication (negative experience)
#8, p.9	They do leak but it's mainly… because of liquid that I take in but I've learnt how to do my stoma, how to put my bag on. I use a lot of paste, the 'Stomahesive' to put the bag on. If I didn't do that it would leak a lot but I change it twice every other night and generally it stays on.	Resourceful in preventing leaks around stoma site (positive experience)
#8, p.9	…. when I'm out if I'm walking about I can't drink unless I have to eat because it's instant – it comes out instantly and I will need to go to the toilet.	Resourceful in avoiding drinks before going out (positive experience)
#8, p.9-10	If we go to a pub or go for something to eat, I like to sit near the toilets because then while I am eating, I can go and empty [the stoma] and then I can come back.	Resourceful in choosing seat in social situation (positive experience)
#8, p.10	Yes, they all know that if we are in a situation where we are eating, I just go to the toilet and everyone knows why.	Disclosing own feelings to others (positive experience)
#8, p.10	One of my aunties' got a stoma. She's got an ileostomy when it's your bowel and she can eat and drink normally and she doesn't go to the toilet like I do. So I sometimes think why did I end up with this….[participant became very upset at this point].	Loss of normality negative experience) Not accepting own situations (negative experience)
#8, p.11	My friends and my family all understand. You do get the look obviously.	Feeling comfortable amongst friends (positive experience) Experiencing 'odd' looks from others in social situations (negative experience)

Participant, page number	Excerpts	Codes
#8, p.11	I obviously don't look disabled and you get some really horrible people out there when I come out from the disabled toilet.	Not recognised as disable in public (negative experience)
	They looked down at me and I thought I'm disabled, I'm allowed to use these toilets.	Discrimination from disable users negative experience)
	Because I'm not in a wheelchair or I'm not using a stick to walk with, I am not old so I should not use the disable toilet.	Discrimination from wheeler chair users (negative experience)
	….strangers don't know what I've got so don't matter where you are, if you are using a disable toilet you get them looks of people, 'Why is she in there?' especially, I know this is awful to say but the people in wheelchairs are the worst.	
#8, p.12	Yes because they made me feel that I should not be in that toilet and I need to be near to a toilet.	Discrimination from other disable users (negative experience)
	I got a key to let myself in so obviously I am allowed to use that toilet.	Needing to justify own actions (positive experience)
#8, p.12	Because of the location of the stoma [point at the middle of the abdomen], I've got no core muscle and my stomach muscles are actually parted and the stoma is slap bang in the middle, so I've got not strength and I can't even push a Hoover.	Loss of physical strength(negative experience)
#8, p.12	My partner does it.	Dependent on help from partner (negative experience)
#8, p.12	I can drive, driving is fine.	Able to drive (positive experience)
	I can't pick up the shopping. I've got no strength so I can't pick things up that are heavy….	Loss of physical strength (negative experience)
	….so I go shopping with A [P8's partner] but he carries everything, puts everything in boot, fetches everything in [from the car].	Dependent on supported from partner (positive experience)
#8, p.13-14	You always got extra stoma stuff to carry with you, just in case you're out and about and you do have a leak.	Being resourceful in coping with stoma leaks in public (positive experience)
	You've got your emergency pack that you take with you.	
	And then if you do leak, you got to try and mend it while you're in a toilet somewhere and then get back to wherever you are.	Coping well with stoma leaks in public places (positive experience)
#8, p.14	Yes, I've had various leaks. It's not nice.	Unhappy with stoma leaks (negative experience)

	It's….you just….get to the nearest toilet and sort it out.	Coping with leaks in public places (negative experience)
Participant, page number	**Excerpts**	**Codes**
#8, p.15	They made me feel like….it's…completely different to a lot of stomas, and…. …. it makes you feel, '*Why me'…..'Why have I got this and why it wasn't just a normal [stoma]*?	Not accepting own situations (negative experience)
#8, p.15	They don't answer it. I've asked them and they just said it was a major ….what happened was why I ended up like I have.	Life changing impact (negative experience)
#8, p.16	I won't want to be like this for longer than I have to. Hopefully they are going to do a reversal if they can.	Not accepting own situation (negative experience)
#8, p.16	The Northern General....I'm waiting….I had my pre-op on 16th April…so it's just a case of Mr A [surgeon] who said, '*All I can do is open you up and see what I can do.'*…so hopefully…he says there is a fifty-fifty chance that I will be able to do or won't. So I will either go back to a normal diet if he can put me back together, or I'll be like this forever.	Realisation of uncertainty (negative experience)
#8, p.16	Upset [P8 became very tearful at this point]. I don't want to think that I'm going to be like this forever. It's very, very restrictive.	Not accepting own situations (negative experience) Loss of normality (negative experience)
#8, p.16 #8, p.17	You can't go anywhere. You can't eat or drink on the move. I can't sit in the car for a long journey. People can eat and drink in a long journey, I can't do that. So I need to be near to a toilet, and when I'm out and about I'm looking for toilet all the time. So it's very restrictive.	Loss of access (negative experience) Loss of choice (with foods & fluids) (negative experience) Loss of own desires (negative experience) Access to toilet facilities (negative experience)
#8, p.17	It makes you feel that you don't want to go out; you just want to stay at home because you're alright at home.	Loss of interests (negatives experience) Staying at home (negative experience)
#8, p.18	We have got a wedding coming up and I know it sounds awful but I am hoping that I'm not fit enough to go [laughs]. Because the whole family will know obviously but then I've got to be in a room with other people who	Humour to disguise anxiety & uneasy in social gathering (negative experience)

	don't know. They will wonder why I keep going to the toilet. I have to keep walking past people when I need to go to the toilet.	Not disclosing own situations (negative experience) Self-conscious & desire to hide stoma (negative experience)
Participant, page number	**Excerpts**	**Codes**
#8, p.19	If they don't know the severity of what has happened, and *I don't think they really understand….the afterlife* if you see what I mean.	Despondent with own situations (negative experience)
#8, p.19	It's just hard to live like this and with all the things I couldn't do.	Loss of own desires & interests (negative experience)
#8, p.19	….but because I got this duojestomy [duojejunostomy], it was difficult because it's not just one thing that I've got to cope with, it's another… ….	Not accepting own situations (negative experience)
#8, p.19	….if it was a proper functioning stoma, I can have something to eat, it would be a couple of hours after I can thicken the paste up and eat normally like normal people. And then a few hours later I can empty the stoma. But I have to do it as I go along. If I have a pack of crisps, I've got to have a drink to let it go down. And then I've got to empty my bag once I've eaten them. Even sucking a sweet can produce a lot of saliva, so even if you in a car, you can't suck a sweet.	Frustration with not being able to eat (negative experience) Malabsorption of food (negative experience)
#8, p.19-20	And then I need a lot of salt because I don't absorb enough, they told me to eat salty foods.	Following dietary advice (positive experience) Changing eating habit (positive experience)
#8, p.20	It's the duojestomy [duojejunostomy] that I can't cope with.	Not coping own situations (negative experience)
#8, p.21	Stoma, definitely stoma.	Frustrated with stoma care (negative experience)
#9, p.6	Yes….how can I explain it….two or three times it has leaked and I put a bag on it and it leaked through. Like this morning, normally I get up three times in the night to make sure everything is empty and everything is alright. Last night I got up just the same, went to the toilet, nothing in the bag what so ever until half past seven this morning. At half past seven I woke up and it's just started to leak through the bottom of the bag and that is the problem. That is the problem with the fistula – you've got to make sure that you empty it at every opportunity so that it does	Lack of control with leaks (negative experience) Troubled by leaks (negative experience) Disrupted sleep at night (negative experience) Anxious about leaks (negative experience) Frustrated with leaks (negative experience) Resourceful in minimising leaks

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	not put weight on it and cause it to leak and that is the problem with a fistula. Real problem especially if you are out and we have had it when it's leaked when I'm out and we carry a spare set of clothing and spare dressings in the car so that at least…with tinted black windows, so that I can get changed in the car, to clean myself up and so forth. But it's definitely a bind and a worry it's going to leak in an opportune moment.	(positive experience) Frequent access to toilet facilities (negative experience) Carrying spare clothing (positive experience) Anxiety & worry about leaks in public places (negative experience)
Participant, page number	**Excerpts**	**Codes**
#9, p.7	Don't let it put me off at all. I got a fistula, and in three weeks today I'm going to Ireland which is going to be a twenty-four hours journey more or less. We should carry the stuff with us like we normally do but hopefully we can watch it and we won't have any problems. It's the same when we go down to Cornwall or anywhere else. We try our best to make sure before we set off the bag is empty there is nothing in it and we watch it on the journey down and there are plenty places to stay, to stop and visit to the services and we can manage it quite well, so we don't have a problem. No problems at all with going away. Nothing will hold me back; ….I will not allow anything to hold me back.	Refusing to compromise (positive experience) Accepting own situations (positive experience) Holidays by car (positive experience) Carrying spare clothing (positive experience) Enjoying social mobility (positive experience) Places with plenty of toilets (positive experience) Restrictions on journey time Frequent access to toilet facilities (positive experience) Refusing to compromise (positive experience) Refusing self-pity (positive experience)
#9, p7	I've got what I've got and I'm prepared to make the best of it. I accept not that I like it. I accept that they will not operate to close the fistula. If they close the fistula I can get rid of the tpn. But they told me my heart wouldn't stand the operation so I have to accept that I'm going to be like this unless they can find another way round it. I just don't think about it. I will not entertain it. I'm going to enjoy life as much as I can and do what I can.	Accepting own situations (positive experience) Accepting own situations (negative experience) Refusing to compromise (positive experience)
#9, p.9	But now I am ill, I can't do that but she accepted that and she works with me and we have a great time, we have a great life together and I couldn't wish for anything better.	Dependent on support from spouse (positive experience)
#9, p.9	It would have been very, very difficult. I would have coped – I'm not the type of person to give in but having C it's been far, far easier because I can talk to her, she will help me, and nothing scars her what so ever. She just accepts this – the fact like this morning when it was leaking, it makes a mess of everything as you can understand. She just accepts it, we strip everything off	Dependent on help & care from spouse (positive experience)

	and get them washed and cleaned. And she doesn't complain one little bit so I cannot argue….she is fantastic.	Grateful with support from spouse (positive experience)
#9, p.10	You've seen this morning yourself. They just act normal, a normal life, no changes what so ever. The only other people who really matter are my brother and his wife, and they accept it for what it is. And that is the one thing I cannot do which is to dress this [the fistula] myself, C has to dress it for me.	Acceptance by family members (positive experience) Unable to self-care (dress fistula) (negative experience) Dependent on wife's help to dress fistula (negative experience)
Participant, page number	**Excerpts**	**Codes**
#9, p.10	Because of the position [P9] was pointing at the middle of his abdomen] I can't bend down and see where to put things. I'll have to use a mirror which I have done but it's very, very difficult. If you get it wrong, you get the mess all over so it's much easier for C to do it and I also got a stoma pouch as well, so there two things to cope with. C copes fantastically.	Unable to self-care (negative experience) Dependent on care from spouse (negative experience) Grateful with wife's support (positive experience)
#9, p.10 10-11	My first reaction was despondency. I really, really was looking forward to having the operation, getting rid of the fistula, and also getting rid of the tpn. [Pause] It was never a nice feeling at all to be told they couldn't operate and my heart wouldn't stand it. And it makes you wonder what the conditions of things are? How…if you want a better word in putting it, how long you've got before your heart packs up altogether. But having said that after twenty-four hours, and having time to reflect and to think about it – '*I've got what I've got, make the most of it, and enjoy life while you can and do what you want to do, don't let anything stop you;….* i.e. we have two cats – we will not put them in the cattery, they go with us.	Despondent with news (negative experience) Disappointment with own health (negative experience) Worried about own health (negative experience) Accepting own situations (positive experience) Maintaining social mobility (positive experience)
#9, p.11	….if we go down to Cornwall, the cats go with us. We're going to Ireland and the cats are going with us and I don't let anything stop us. So we take them with us and they enjoy just as much once they have settled in, no problem. We find it a much better system so that's how we do. Nothing stops us doing what we want to do.	Taking holidays (positive experience) Refusing to compromise (positive experience) Enjoying social mobility (positive experience)
#9, p.11	Nothing at all if I can help it. Yes, we've had little setbacks i.e. if we decided to go somewhere and then we had a leak, which would stop us going but….other than that nothing stops us. We decide what we want to do during the day; we get on and do it. It includes going shopping or whatever then we go shopping and [laughs] I just cannot imagine letting this thing stops me.	Refusing to compromise (positive experience) Enjoying social mobility (positive experience)

	As I say I don't like having it and I'll love to be without it but it's not to be so unless they can come up with a different idea…. it looks like I'm going to be stuck with it. So make the most of it and enjoy what you've got.	Accepting own situations (positive experience) Refusing self-pity (positive experience)
#9, p.12	I have a list of tablets a mile long. The only one I take for managing the fistula is Imodium or Loperamide is the other name. I take eight tablets four times a day and that's the only one to control….trying to thicken the stuff up.	Understanding need for medicines to thicken output (positive experience)
#9, p.13	I take them as soon as I get up in the morning when I take a set of tablets including the Loperamide. Dinner time, Loperamide; tea time, Loperamide; night time before going to bed, Loperamide that's my four times; and I do that every day sort of thing.	Understanding when to take medicines (positive experience)
Participant, page number	**Excerpts**	**Codes**
#9, p.13	And because I am a naughty boy, although they told me that I haven't got to take anything by mouth or nil by mouth, I am sorry but when people are sitting down to a Christmas dinner and I can't have any. No, so I have my Christmas dinner and I have a little bit of food as well as the HPN. So when I have my food then I take my tablets. [This was followed by a lot of laughs from P9].	Taking risks (negative experience) Satisfying own desires (positive experience)
#9, p.13	Yes, not to eat or drink….can you imagine that? Oh, I do not accept it.	Satisfying own desire (positive experience) Refusing to compromise (negative experience)
#9, p.13 13 - 14	I just told them that I've been a naught boy like I explained to you that I do have little bit of what not in between. Yes, that's it. I have nice cream cake or whatever and I do watch what I eat if you understand me. But if I fancy, hang on a minute, I'll have one of them [with a smile from P9].	Taking risks to satisfy own desire (positive experience)
#9, p.14	If I have soft fruits or something like that, not a problem. If I have a currant or that type of thing in a piece of cake, I can't get rid of it and it comes out as it went it. And it can block the hole up as well until it actually forces its way through~~.~~	Trial & error with dietary advice (positive experience)
#9, p.16	[Long pause]. Ah…how would I summarise my quality of life? So living with the fistula, the stoma and what not, it is [long sigh]….how can I put it….*it's a bind*. But you've got to put that to the back of your mind, you've got to forget about it….pretend it's not there and for ninety percent of the time during the day and what not I, I can do that, I don't think about it.	Frustration with fistula (negative experience) Refusing self-pity (positive experience)

	But all of a sudden you'll find that it's…when the bag's blown up or it's filling up it must be emptied, that brings me back down to earth for a few minutes. But the moment it's emptied and everything is okay, I forget completely all about it and I don't accept it's there and it gets me through really well. I don't have to, I don't worry about it but when something happens, it does worry me…. …. because nine times out of ten, it's not me who has to clean the thing up, it's C.	Frustration with fistula care & leaks (negative experience) Accepting own situations (positive experience) Worried about fistula leaks (negative experience) Dependent on care from spouse (negative experience)
Participant, page number	**Excerpts**	**Codes**
#9, p.16	Alright it's…how can I put it….this is between you and I, there is no sex now because of the situation but ….	Loss of physical intimacy with spouse (negative experience)
#9, p.17	Recognisable tablets coming back out. I can eat a pea and it will not be digested and it will come straight back out. That's an ordinary garden pea. I shall have to watch what I eat in that respect. What we found out through experience, what you can have.	Malabsorption of medications and foods (negative experience) Dietary restrictions (negative experience) Trial & error (positive experience)
#9, p.17	No, nothing is going to hinder me. Okay there are times when you get down and you're feeling depressed…or '*God, I wish I hadn't got this*',	Refusing to compromise (positive experience) Depressed with own situations (negative experience)
#9, p.17	…. but then you bounce back and you think well, there's a hell of a lot of people who are a lot worse off than me, like people who have lost both legs or a limb or whatever, and they are in far worse position than where I am. *Alright it's a bind having these things, but so what*? [laughs].	Refusing self-pity (positive experience) Accepting own situations (negative experience)
#9, p.19	I was offered to join a group, just for discussions and things like that both on stomas and on HPN. No. As I say we accept what we've got, C and I. Yes, I suppose if it came down to me being on my own that would be a different matter. I'll probably join them and get into discussions with different people, find out how	Being offered information on patient self-help groups (positive experience) Not interested with self-help groups (negative experience)

	they are coping. But at the moment I don't need that, I have C – we can discuss anything and we don't need anybody else.	Good communication with spouse (positive experience)

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What process is at issue here?

All participants (#1, 3, 5, 7, 8 & 9) experienced the impact of high losses from stoma. The stoma care affected their lives in many ways both at home and socially. The two noticeable features were: the need for frequent access to toilet facilities and the need to cope with leaks and accidents.

Under which conditions does this process develop?

In order to reduce the losses, they had to face two issues: dietary & fluid restrictions and medicines to reduce volume & frequency. They shared similar experiences in coping with the lack of dietary choices and the need to learn by trial and error with foods and fluids. Despite their efforts to change their eating habit, they all experienced weight loss and loss of physical strength.

How do(es) the research participant(s) think, feel, and act while involved in this process?

All participants struggled to cope with the life changing impact the stoma as the consequence of sudden illness. Two participants lost their job with one of them struggling with financial burden. Their coping strategies were reflected in the following aspects of their lives: social impact, dietary impact and emotional impact.

When, why, and how does the process change?

Whilst all participants experienced lack of control of high losses from stoma, fistula or chronic diarrhoea, those who accepted their own situations appeared to be more resourceful' and confident with self-care, and were able to satisfy their own desires in terms of social mobility, holidays by car and refusing to compromise.

Four participants (#1, 7, 8 & 9) were dependent on care, help & support from spouse / partner. However, only participant #1 and #9 showed determination to refuse self-pity and they felt confident in disclosing own situations to family members and close friends.

Participants #5, 7 & 8 did not accept their own situations and they were unwilling to disclosing own feelings to others. They were self-conscious with desire to hide stoma (chronic diarrhoea in the case of #5) from others.

Participant #8 experienced verbal discrimination from wheelchair users when using toilets designated for disable users. This was an extraordinary disclosure and it reflected the extent of her frustration and loss of normality with her own situations.

What are the consequences of the process?

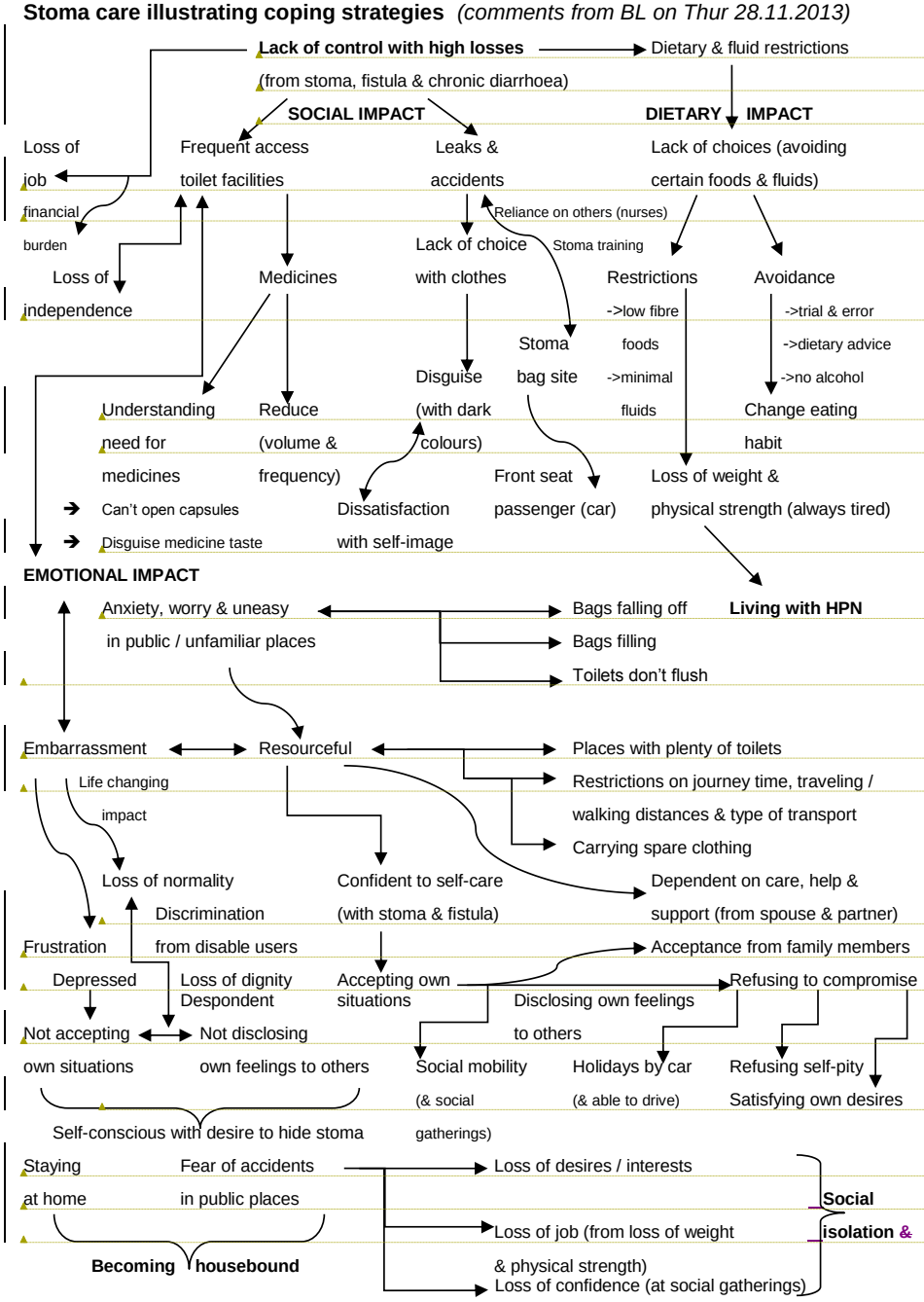
All participants experienced significant emotional impact in their lives. However, those who experienced frustration, felt depressed with the loss of normality and poor self-image were least able to accept own situations or disclosing their own feelings to others. They were staying at home with the fear of accidents in public places, and as the result they become housebound with the loss of desires / interests to go and do things that they used to enjoy, loss of confidence at social gatherings and the loss of job due to loss of weight and physical strength.

Category: Stoma care **Thur 21.11.2013**

Open codes on stoma care were analysed across participants #1, 3, 5, 7, 8 & 9. These codes revealed d what was happening and what the participants did in similar situations

using the method of axial coding (Strauss & Corbin, 1998 p.123-124) and selective coding (Strauss & Corbin, 1998 p.143-144) to guide future direction of data collection.

Stoma care illustrating coping strategies *(comments from BL on Thur 28.11.2013)*



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Notes from supervisors meeting on Thur 28.11.2013

1. Detailed discussion on axial coding and selective coding as described by Strauss & Corbin (see reference below).
2. Retrieve open codes on 'reliance from stoma care nurses' when learning to self-care for stoma. Include these in Diagram 3.
3. Locate book from UoB library for further reading on these analytical techniques.
4. Apply these techniques with the next categories on 'TPN characteristics' and 'TPN coping strategies' in memo 4 for discussion at next meeting on Thur 23.01.2014

Own notes on definitions

Axial coding (Strauss & Corbin, 1998 p.123)

The process of relating categories to their subcategories, termed axial because coding occurs around the axis of a category, linking categories at the level of properties and dimensions.

The paradigm

An analytic tool devised to help analysis integrate structure with process.

Structure

The conditional context in which a category (phenomenon) is situated.

Process

Sequences of action / interaction pertaining to phenomenon as they evolve over time.

Useful quotes

p.124-125

Procedurally, **axial coding** is the act of relating categories to subcategories along the lines of their properties and dimensions. It looks like how categories cut crosscut and link.

A **category** stands for a **phenomenon**, that is, a problem, an issue, an event, or a happening that is defined as being significant to respondents.

The phenomenon under investigation might be as broad as negotiating a peace agreement between two nations or as narrow as self-perceived body image changes after an amputation.

A phenomenon has the ability to explain what is going on.

A **subcategory** also is a category, as its name implies. However, rather than standing for the phenomenon itself, subcategories answer questions about the phenomenon such as when, where, why, who, how and with what consequences, thus giving the concept greater explanatory power.

Early in analysis, the researcher might not know which concepts are categories and which are subcategories. This usually becomes evident as coding proceeds.

Questions to ask after each interview: **What seems to be going here?**

Although the text provides clues about how categories relate, the actual linking takes place not descriptively but rather at a **conceptual level**.

p.126

Procedurally, axial coding involves several basic tasks (Strauss, 1987 Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: University of Cambridge Press.)

These include the following:

Laying out the properties of a category and their dimensions, a task that begins during open coding.

Identifying the variety of conditions, actions / interactions, and consequences associated with a phenomenon.

Relating a category to its subcategories through statements denoting how they are related to each other.

Looking for cues in the data that denotes how major categories might relate to each other.

Reference

From UoB library (WY20STR)

Strauss, A & Corbin, J. (1998) *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, London: Sage Publications.

Appendix 11b Theoretical memo 4 open codes on HPN

01.12.2013

Open codes on HPN were collected concurrently from each interview transcript. The HPN was a common theme in subsequent transcript for participants #1, 3, 5, 7, 8 & 9. These codes were analysed concurrently using focus coding and they revealed information on HPN and its impact on the participants' lives at home and in social situations. These excerpts and their open codes were tabulated in order to illustrate all the features associated with HPN. I followed the method of axial coding described by Strauss and Corbin (1998 p.123) which supported the identification of the phenomenon HPN, its characteristics and corresponding properties. The same coding techniques were used to reveal information on the way these participants coped with HPN treatment at home and in social situations. The excerpts were underlined in order to reflect the open codes generated from the interview transcripts.

Open codes on HPN (#1, 3, 5, 7, 8 & 9)

Participant, page number	Excerpts	Codes
#1, p1-2	Dr P said because these fluids are not suiting me I am talking two or three years right at the most and then I will start going jaundice then.	Jaundice as side effect from HPN long term (negative experience)
#1, p.2	I don't like being on long term for twelve hours in here every day. We have not been able to go away or holiday, you know what I mean stuff like that and I find it quite binding …	HPN infusion over 12hrs (negative experience) Unable to have holidays away from home (negative experience) Lack of choice (negative experience)
#1, p.3	I don't feel as poorly. I'm feeling quite well and I look quite well. And everybody says I look quite well.	Improved wellbeing & appearance (positive experience)
#1, p.3	I don't like it, I'm restricted.	Restriction from HPN routine (negative experience)
#1, p.3	So if I'm going out and I get back at half twelve, you've got to put the stuff on at half twelve, it's a bind.	Feeling forced to comply with HPN infusion time (negative experience)
#1, p.4	you go to the toilet to empty stoma and you're carrying that to toilet, oh and then at night you got night bag on and then you got HPN stuff you know what I mean, you feel a bit.. you don't feel… you feel unattractive do you know what I mean, with all this on.	Feeling unattractive (negative experience)
#1, p.4	My husband puts me on it; I have to take myself off it. I do that because he puts it on at twelve and he has to click the bottom off and it's like a blue fastener, and I find it hard for me to take that off. So Keith always does that, and then he gets that wire,	Dependent on spouse to set up HPN (negative experience)

	Hickman mm…….that line and he changes me Hickman line. All I do is take me of it.	
#1, p.7	But Keith puts me on it, I don't like it and I always think it's a bind and but I know I've got to be on it.	Feeling forced to accept help from spouse to set up HPN (negative experience)
Participant, page number	**Excerpts**	**Codes**
#1, p.7	I seem to have a problem here. I was a bit [P1 rolled her eyes and appeared fed up] when I have to go on it [HPN], because then I have to carry it [HPN] all night. If I go to the kitchen, I have to carry it; I want go upstairs I got to carry it upstairs. I'm just tired of it; I'm not used to being tired.	Having to carry HPN bag around at night (negative experience) Restrictions on mobility around the house (negative experience)
#1, p.8	Well I won't be dehydrated will I? But it's still going to cause me more jaundice.	Health improvement from HPN (positive experience) Awareness of & accepting jaundice (as side effect) caused by HPN (negative experience)
#1, p.13	Once you put these HPNs on at night and you are pulling it around, you get fed up of doing it. I don't, I don't like it but I got to have it for my own benefits, I know that.	Pushing HPN pump around at night (negative experience) Restrictions on mobility around the house (negative experience)
#1, p.13	Going out. Being able to go out, just taking off when you want. You know you have to just go out in the morning, stay out all day.	Loss of freedom (negative experience)
#1, p.14	I don't like it. I really don't like. I have to have it.	Refusing to accept own situations (negative experience) Lack of choice (negative experience) Feeling forced (negative experience)
#1, p.14	I am just an independent person…. I'm just one of these that I want to go out, and go away and it's affected me probably more than them.	Loss of independence (negative experience) Unable to go out (negative experience)
#1, p.14	If I haven't on it, I just feel dehydrated and I will end up in hospital, so I've got to be on it.	Dehydration without HPN (negative experience) Dependent on HPN (negative experience) Realisation of health benefits from HPN (positive experience)
#1, p.16	I think it's more of a social thing for me, you can't, you can't go out, or you'll have to go out and come back and have it put on at eight or you have to wait	Loss of social life (negative experience) Feeling forced to comply with

	when you come home and start putting it on. And then it's till the next day or till whenever.	HPN routine (negative experience)
#1, p.16	I'm so restricted ……. plan around stoma and ….you empty stoma and then at eight o'clock you go to bed with HPN and stoma, and then when you get in bed you got night bag on and you got stoma and you got Hickman line – I don't……it's not very…….I probably think I'm a lot younger than I am you know.	Frustrated with restrictions from HPN (negative experience) Dissatisfaction with self-image (negative experience) Disappointed with changes in self (negative experience)
Participant, page number	**Excerpts**	**Codes**
#3, p.9	I can't …once I'm connected, I like to be off it early in the morning, so that I can get up and get dressed without dragging everything with me.	Restriction on mobility with HPN running (negative experience) Choosing HPN start & finish time (positive experience) Able to go out once HPN has finished (positive experience)
#3, p.9	It's really restricting you can't go out in the evenings.	Unable to go out at night (negative experience) Loss of social life (negative experience)
#3, p.9	It's quite a heavy bag to carry around with you all the time …. ….so I tend to sit in the evenings so that's made quite a difference.	Struggling with heavy weight of HPN bag (negative experience) Resourceful in coping with weight of HPN bag by being seated (negative experience) Staying at home with HPN running at night (negative experience)
#3, p.9	Every night. I have fluid one night and HPN the next.	Understanding HPN & IV fluid frequency (negative experience)
#3, p.9-10	Twelve hours so I go on about quarter to seven, seven o'clock well I start about quarter seven and then I can get up at seven [the following morning] and start with the stoma and do all that and then disconnect. (Pause) I'll have a shower (laugher).	HPN infusion over 12hrs (negative experience) Choosing when to start and finish HPN (positive experience) Confident with HPN routine (positive experience)
#3, p.10	The nurses from Willow, the company I have the supplies from, they came for the first probably five days to make sure that I could do everything because the battery was a different system and I have never connected to a battery.	Supervised by homecare company to set up HPN at home (positive experience)

#3, p.10	they came and make sure I could do everything properly and then.. I could always ring if I needed them.	Assessed by homecare company to set up HPN safely at home (positive experience) Access to telephone helpline provided by homecare company (positive experience)
#3, p.10	I had to ring, I think it was the week before last, because one of the fittings on the tubing was leaking and I didn't know whether to wrap it up, I couldn't really go to bed because it was leaking too much.	Help & advice from homecare company to sort out technical problems with HPN pump (positive experience)
#3, p.10	they told me to disconnect, get a new bag out, wait two hours and then reconnect so it was quite (laughter), quite a night.	Technical support & advice from homecare company (positive experience)
Participant, page number	**Excerpts**	**Codes**
#3, p.10	They [Willow staff] were very helpful I mean somebody at that time of night rang me straight back and told me what to do and to ring if I had any further problems so I felt I have got somewhere I can turn.	Reassured and supported by homecare company (positive experience)
#3, p.11	Just the evenings I can't go to theatre or cinema or anything that I used to do now and again with a group of friends.	Loss of social life at night (negative experience) Frustrated with being house-bound (negative experience) Loss of friends / social contact (negative experience)
#3, p.11	I can't go away for a weekend or even overnight.	Unable to go away (negative experience) Unfulfilled own desires (negative experience)
#3, p.11	that's restricting because my daughter and I used to go quite often for a weekend with friends.	Frustration with strict HPN routine (negative experience) Loss of social contacts (negative experience)
#3, p.11	Taking all that with you, I can't see that you can really go away overnight even .. because it would be too… too difficult…	Dissatisfaction with amount of HPN equipment (negative experience)
#3, p.11	take the trolley and then all the bags and things that you have to take and equipment to actually disconnect and disconnect, and then the stoma bags, disposal everything like that would be very awkward.	Inconvenience from amount of HPN equipment (negative experience)

#3, p.11	I wouldn't want to do that I don't think.	Choosing not to take holidays (positive experience) Unfulfilled own desire (negative experience)
#3, p.12	when I went to another meeting with Dr Page, would it be possible to be off for one night so that I could have a break and he said no. So I didn't go into any more.	Dependent on HPN 7 nights a week (negative experience) Accepting own situations (negative experience)
#3, p.12	I can cope with the stoma but there's nothing I can do about the HPN. I've got to be here [at home] to do it.	Lack of choice (negative experience) Accepting own situations (negative experience) Feeling house-bound at night (negative experience)
#3, p.14	I can't manage the drip stand up and down the stairs and I don't want to stay upstairs all evening.	Struggling with weight of drip stand upstairs (negative experience) Loss of mobility around the house (negative experience)
Participant, page number	**Excerpts**	**Codes**
#3, p.14	I have a portable pump in a rucksack but it's heavy.	Struggling with weight of rucksack for portable HPN infusion pump (negative experience)
#5, p.3	I was told by Miss P that I was going to be transferred to Sheffield to learn HPN.	Lack of training for HPN at home locally (negative experience) Accepting need for transfer to Sheffield for HPN training (positive experience) Lack of choice (negative experience)
#5, p.3	It only took two days.	Learning to set up HPN quickly (positive experience)
#5, p.3	I used to work with hydraulics so basically this is just a pump so I knew what I was doing. It was just the aseptic part keeping everything clean that needed a bit more time for me to learn.	Confident to set up HPN at home (positive experience) Learning aseptic technique to self-care (positive experience)
#5, p.3	The HPN training was a lot easier than learning to put a colostomy bag on. The number of times I couldn't get the bag to stick to my stomach or if I move in a certain way the bag will come off. The HPN training was a lot easier.	Learning to set up HPN quickly (positive experience)

#5, p.4	I didn't. I got a niece who is a district nurse and she handed the key to Willow, the healthcare company, and set everything up… …..and it was all here waiting for me when I came out of hospital.	Accepting help from relatives to sort out homecare company (HCC) deliveries (positive experience)
#5, p.5	They put the fridge in a place, the axillary for ……my dressing packs and the giving sets and everything in a set of drawers.	Taking part to sort out storage space for HPN equipment (negative experience)
#5, p.5	The home HPN was easy.	Confident in managing HPN at home (positive experience)
#5, p.5	When I first came home, I was on fifteen hours a day, seven days a week. In 2012 Dr Kevin Page changed my prescriptions and put me on every other day, twelve hours a day and I've been on that ever since. So it's twelve hours a day every other day.	HPN infusion for 15hrs every day (negative experience) Reducing HPN to 12hrs on alternate nights (positive experience) Accepting own situations (positive experience)
#5, p.6	Well, it was fifteen hours a day. and I just could not go anywhere, completely anywhere.	Resenting 15 hrs a day for HPN (negative experience) Limited mobility with HPN running (negative experience) Social isolation (negative experience)
Participant, page number	**Excerpts**	**Codes**
#5, p.7	Which I don't know whether it was that last night when I turned in bed I don't know. But when I woke up this morning that [HPN feed] was still full [P5] was pointing at the HPN bag which was connected to a portable infusion pump attached to a mobile infusion stand]. I don't know what time it ended up tripping off. I don't if I've lied on it or caught it, and it alarmed and turned itself off, I don't know. You only have to do this [P5 was bending the plastic tubing for a few seconds] and it alarms.	Experience with HPN pump malfunction (negative experience)
#5, p.10	Lifting the bag is awkward especially with my elbow. My wrists, elbows and shoulders are always hurting.	Struggling to lift HPN bag (negative experience)
#5, p.10	The drip is high up and I lower it as far as I dare lower it but it does get really heavy that bag when it's a full two litres. I do struggle to get it on the drip stand.	Resourceful in lowering height of drip stand (positive experience) Struggled to lift HPN bag onto the drip stand (negative experience)

#5, p.15	Even though I have it on twelve hours a day I usually put it on at night and I have it overnight.	HPN infusion over 12 hrs at night (negative experience) Choosing when to start and finish HPN (positive experience)
#7, p.8	I can....I think it was a mixture of the doctors talking about it [the need for home HPN] and one of the surgeons and then the two HPN nurses, H & S, who came and discussed it. And it just seemed so over-helming because obviously you sat watching the nurses do this procedure that seemed so complicated, so hygienic, I *just thought 'Gosh there is no way I'll be able to do that by myself'*.	Over-helmed with practicalities of setting up HPN (negative experience) Lack of self-confidence in learning to set up HPN (negative experience)
#7, p.9	My experience of the actual training itself – it was good, I found it very thorough and I was quite anxious about it at first. I've got the instructions but I thought I'll never be able to remember all this.	Satisfied with HPN training from homecare company (HCC) (positive experience) Becoming less anxious & more confident to set up HPN (positive experience)
#7, p9-10	I remembered the very first day that I have some training with S [HPN clinical nurse specialist] and I think I messed things up just opening the gloves or something and that was at the very beginning of the procedure and I thought, 'God, I've all that to go through, how the hell am I going to get this into my head?'	Realisation of complexity in learning to set up HPN (negative experience) Lack of self-confidence (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.10	And I think at first I was panicking because I think they gave me the instructions and just reading through the instructions I found it quite stressful because they were things that, the instructions were referring to things….I thought what's that, the terminology. And I thought I'm really tired and I'm really exhausted and I've got to try and absorb something that sounds really technical and doing it as well never mind reading. I find reading about it difficult. So I spoke to H [HPN clinical nurse specialist] about it, she said, 'Don't worry, we'll explain what all the terminology is about; what is it that you are finding difficult?'. I went through them and she explained what everything was. She said don't worry about it, don't get caught up in things, not understanding things, you will by the time you finish you will. So to actually go through the practicalities from the very beginning to reading the instructions with the nurse, it was good. I thought the training was excellent. It was really	Daunted by new information (negative experience) Struggled with unfamiliar names (negative experience) Struggled with unfamiliar clinical / technical names (negative experience) Reassurance & help from specialist nurse (positive experience) Becoming confident with training & support from hospital specialist nurse (positive experience) Satisfied with excellent training from hospital specialist nurses

	thorough.	(positive experience)
#7, p.11	It was the first couple of times, I think I was quite anxiety riddled and after that it was more trying to remember things and getting anxious when you did something wrong, putting gloves on at the wrong stage or read something wrong. If at that point you find that you're doing something wrong, I just start again. So I found them [HPN clinical nurse specialists] very supportive and very good training.	Anxious with learning to set up HPN (negative experience) Well supported by specialist nurse (positive experience)
#7, p.13 #7, p13-14	I think that was decided upon with my partner because I knew that they were bringing all the equipment whilst I was still in hospital. So basically I was told that we need some sort of power point and space to do things so I discussed it with my partner and we need to think about where the hell we are going to put it because we got no room. So he said he would sort out some room in his office and we could store everything up there because it was the room next to the bathroom as well and then we could close the door and hide it all away.	Realisation of storage space for HPN equipment at home (negative experience) Dependent on help from partner (negative experience) Resourceful in making storage space available (positive experience)
#7, p.14	But apparently when the fridge came, I think we were both surprised, I think we were both expecting it to be a under the counter fridge, I don't think that was quite explained properly because I can remember him [P7's partner] was saying the fridge was huge, it was absolutely massive, it was a good job I cleared the corner out because that was the only place for the fridge.	Realisation of disruptions at home (negative experience)
Participant, page number	**Excerpts**	**Codes**
#7, p.14	So it does feel like, sometimes it can feel like it has taken over a little bit because you end up ordering all the ancillaries and at the moment even though we keep a lot of stuff in the small bedroom that's just the drip stands - two drip stands, a trolley and the huge fridge and all the stoma boxes are on top of the fridge. But in the bedroom one of the wardrobes is where I keep all the ancillaries because there is nowhere else to keep them. So even when you are relaxing in your own room, it's there to remind you just boxes and boxes of stuff so you do feel it's a bit, not over-helming but there is no escape from it.	Realisation of the large amount of equipment to keep (negative experience) Being reminded of own situations (negative experience)
#7, p.15	So it was a relief to be out of hospital to be able to sit, it was just lovely to be able to put your pyjamas on and watch TV and know that I could sit and watch it until whatever time that I wasn't clock watching thinking I've got to go back to the hospital. So it was just such a comfortable feeling, then….	Enjoyed freedom at home (positive experience) Felt comfortable at home (positive experience)

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	….that realisation there were still things on-going because I still got the HPN to do so it wasn't just a sit down and relax and it was a. '*What time is it, I have to start getting ready*'.	Feeling forced to comply with HPN routine (negative experience)
#7, p.15	I was on four nights a week that was Sunday, Monday, Wednesday and Friday. I am still on four nights a week on the same days.	Dependent of 4 nights of HPN a week (negative experience)
#7, p.16	And I think sometimes I'm finding it easier to sleep in the afternoon, one because I'm so tired, two when you go to bed when you got the stoma and you got the HPN as well, your sleep is disturbed so much you are either going to empty the stoma or I think I've got to go and empty it I'm so conscious of it leaking that every time it's filling up a little bit I must go or the HPN makes you want to go to the toilet. Your bladder fills up more quickly because you've two litres of stuff going through overnight. So particularly on HPN night, it's like a double whammy – it's not just the stoma, it's the HPN as well.	Disrupted sleep from changing stoma bag and having HPN running overnight (negative experience) Need for frequent toilet visits from high volume of HPN running overnight (negative experience) Struggled to cope with stoma on nights having HPN infusion (negative experience)
#7, p.23	I feel better because of the feed that's helping me as well. When I see people that I've not seen for a few weeks they can tell that I've put weight on or they'll say, 'Have you put weight on? You looked like you have put weight on. You look better in your face'.	Improved physical health with HPN (positive experience) Improved physical appearance with HPN (positive experience)
#7, p.26	Although I'm thankful that all these that I have the HPN and the stoma have helped me, have saved my life. I still feel like my quality of life has lessened dramatically because whereas before there are no restrictions, there is no routine.	Accepting life-saving effect from HPN (positive experience) Realisation of reduced quality of life (negative experience) Resentful of restrictions & routine from HPN (negative experience)
Participant, page number	**Excerpts**	**Codes**
#8, p.2	They told me I would be on HPN for quite a while, and I've been on it fourteen months. I've been on it since 23 April 2012.	Accepting own situations (positive experience) Dependent on HPN long term (14 months) (negative experience)
#8, p.4	Obviously I had to come home because I was in Barnsley Hospital for six months and they explained to me that Barnsley Hospital wasn't a teaching hospital so they could not train me even though I've seen them doing it a hundred million times. Because I could have done it myself in my sleep. I have to go for proper training and Barnsley doesn't	Lack of training for HPN at home locally (negative experience) Realisation of need for inter-hospital transfer for HPN training (negative experience) Being transferred to Sheffield for

	do the training so that's why I had to go to Hallamshire.	HPN training (negative experience)
#8, p.4	Well obviously because I have….I've got this duojestomy [duojejunostomy] , I obviously don't take anything in, nothing goes down, no nothing at all goes down even water, all comes out into a bag. *So if I don't have HPN I'll die…that was explained to me that HPN is actually keeping me alive*.	Realisation of own situations (negative experience) Accepting need for HPN to stay alive (positive experience)
#8, p.5	You've got to be very sterile….so they got to train me how to put gloves on….because it goes into your vein so in doing that I have to be sterile when I put myself on and then I take myself off, to stop any infection because the line is near your heart. If you get an infection it can kill you.	Learning & understanding sterile techniques to set up HPN safely (positive experience) Understanding risk from life-threatening infection (positive experience)
#8, p.5	It was relatively easy really because at *the end of the day you don't want to die so you've got to do it*.	Choosing to set up HPN safely to stay alive (positive experience)
#8, p.5	Yes, I've done it now since September last year, so it's a good nine months.	Dependent on HPN long term (9 months) (negative experience)
#8, p.5	It's a bit nerve racking the first time you do it but I think it's worse with the nurses are here because you have a home care visit when you first go home. They don't sign you off until they think you are ready but I only had three days with the home care visit before they would let me do it on my own. Yes, I got to grips with it almost straight away and my partner does it as well. He has to learn to do it as well.	Feeling nervous with HPN at home initially (negative experience) Being assessed by homecare company for competency to set up HPN (positive experience) Confident in learning to set up HPN safely & quickly (positive experience) Having partner trained to set up HPN (positive experience)
Participant, page number	**Excerpts**	**Codes**
#8, p.6	Yes. They explained everything first to me. The homecare team, the lady who was in charge of that came to see me. She explained that they have to, I have to have the equipment at home, they have to deliver all the equipment before I could go home. I order everything every fortnight and I get a delivery every fortnight. Yes. Where the fridge goes is up to you. Where you do your procedure is all up to you.	Realisation of amount of HPN equipment to keep at home (negative experience) Choosing to be involved to sort out homecare deliveries (positive experience)

#8, p.6	They were good. They were absolutely brilliant. All the doctors and nurses were nice. They explained everything as they go along. Why you are doing it, why you've got to do it and especially the sterile bit. They have to make sure you know that if you're not sterile, you would or you could get an infection and that could kill. And that is the main thing; it's the sterile bit and the keeping the line clean that they want you to know.	Satisfied with information from healthcare professionals (doctors & nurses) (positive experience) Sterile technique assessed by specialist nurses (positive experience) Awareness of life-threatening infections (positive experience) Understanding importance of sterile technique (positive experience)
#8, p.6	It rules your life; you've got to live around it. It's a case of you live or you die so everything revolves round it.	Dependent on HPN to stay alive (negative experience) Accepting HPN is a life-saving treatment (negative experience)
#8, p.6	At night I put my HPN up between seven and eight. I usually put it up at seven. I got up early and I like to get it off early and it's a twelve hour thing. They let you decide how long you want to have it over but the least time you have is over twelve hours. You can have it during the day or during the night; it's entirely up to you.	HPN infusion over 12 hrs at night (negative experience) Choosing when to start and finish HPN (positive experience)
#8, p.6 7	I like it over twelve [hours] because then I'm free for the rest of the day. I also have water and glucose solution which I have over four hours a day because I don't take no water, I don't take anything in so I get very dehydrated.	HPN infusion over 12 hrs (negative experience) Fitting HPN around life-style (positive experience) Having additional intravenous (IV) fluids to relief dehydration (negative experience)
#8, P.7	When I first came home it was seven [nights] because I've not put any weight on and I kept dropping my weight. I'm still on seven nights now.	Dependent on HPN 7 nights a week (negative experience) Unable to reduce HPN frequency (negative experience)
#8, P.7	I know I used to put on myself in hospital and I have to ask somebody, 'Can you get my feed out at five [o'clock], I want to put it on at six. It's got to be out for an hour before I can put it on'. So it's easier because it's your…you're in control of it at home, you can do when you want to do it.	Frustrated with inflexible arrangement in hospital (negative experience) Choosing when to start and finish HPN (positive experience)
Participant, page number	**Excerpts**	**Codes**
#8, p.12 13	A helps a lot with that because they're [HPN bag] heavy – they are two litre bag of fluid, it's heavy. He gets the feed out every night, an hour before, and we get ready to put it on and he actually puts the line for me because I can't shift the line in because it's	Unable to lift heavy HPN bag (negative experience) Dependent on partner's help to set up HPN (negative experience)

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	hard and I don't have the strength to put the giving set into the bag. And then in the morning he takes it off.	
#8, p.20	Having with HPN is very restrictive but I think you can actually live with it if you haven't other things else. I think if a person is just on HPN for other reasons, I think that is easier to work with but restrictive.	Finding HPN restrictive (negative experience) Coping well with strict HPN routine (positive experience)
#9, p.2	I had comprehensive training over four weeks and it was okay. We had no problems with it at all.	Comprehensive HPN training from hospital special nurses (positive experience)
#9, p.2 2-3	Prepares the surface which is got to be sterile. We sponge down the equipment, the nozzles, we flush them out with saline flush and then we wrapped it up like that [P9 was showing me the two endings of the dual lumen Hickman line] with sterile gauze wrapped round it and then taped up so that it's nice, neat and tidy keeping it sterile. C [P9's wife] will do all these but for a while now I have been doing it in the morning. I'll be uncoupling it and C couples me up in the evening. It goes over twelve hours at night.	Learning and understanding sterile technique for setting up HPN (positive experience) Depending on wife's help to set up HPN (negative experience) HPN over 12hrs at night (negative experience)
#9, p.3	C [P9's wife] wants to be involved …. ….and it was our decision to be involved both of us so we share the duties between ourselves.	Accepting wife's decision to help with HPN (positive experience) Mutual decision with wife to manage HPN together (positive experience)
#9, p.3	Seven nights. Every night….five nights of feed and two nights of fluids every week. We usually start at eight o'clock at night and uncouple at eight the next morning.	5 nights HPN and 2 nights IV fluids a week (negative experience) HPN infusion over 12 hrs at night (negative experience)
#9, p.3	We felt apprehension at first because we didn't know whether we were going to be able to manage it or not. But as the weeks progressed through our training, we found out it was actually quite easy and we had no problems what so ever.	Feeling apprehensive about learning HPN initially (negative experience) Reassured with HPN training (positive experience) Confident to self-care (positive experience)
Participant, page number	**Excerpts**	**Codes**

#9, p.5	In the first twelve months I had no problems with it [HPN] at all. Since I've had it this time, since from December, one night something was wrong and it didn't deliver the feed. But the next night it was perfectly alright and it just delivered like normal. So what that one hiccup was, we don't know. It's worked okay ever since and that's the only problem we've ever had with it. The pump is fantastic. It's not obtrusive, it's small and when you got it on in the bag, nobody knows that there is a pump in there.	Coping with infusion pump malfunction at night (negative experience) Trouble-free with HPN at home (positive experience) Choosing to keep HPN bag & pump discrete (negative experience)
#9, p.5	It's very rare that I put it on my back in the house. I just carry it with a carrying handle [infusion stand]. That can be awkward at times like the stairs because you can get your feet tangled with the line [infusion giving set] and I have to be very careful that I don't slip on it as well.	Struggling to carry heavy HPN bag and drip stand upstairs (negative experience) Fearful of tripping over equipment (negative experience)
#9, p.5 6	It's two thousand….two litres two hundred [millilitres]. It's very, very heavy…very heavy when it's full. And the next morning when it's lighter, I can pick it up and carry it about. It is heavy there is no doubt about it	Struggling with heavy weight of HPN bag (negative experience)

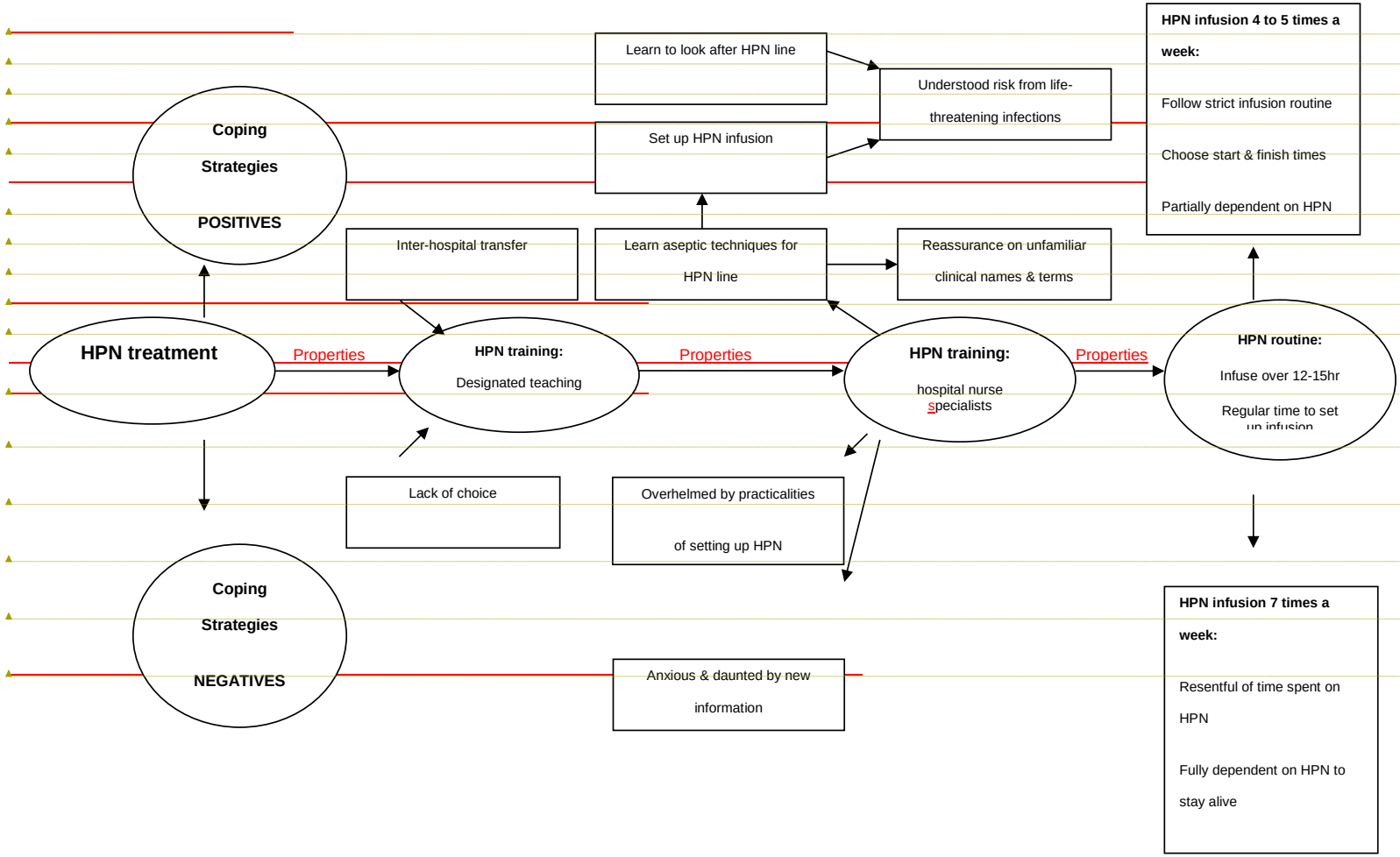
Category: HPN treatment illustrating coping strategies **Thur 02.01.2014**

HPN treatment	HPN Coping Strategies
Properties & dimensions	
HPN training at designated teaching hospitals:	
_inter-hospital transfer for HPN training	Lack of choice
HPN training from hospital nurse specialists:	
_to learn aseptic techniques	Overhelmed by practicalities of setting up HPN
_to set up infusion	Anxious & daunted by new information
_to learn to look after HPN line	Reassurance on unfamiliar clinical names & terms
	Understood risk from life-threatening infections
HPN routine:	
_infuse HPN bag (+IV fluids) over 12-15hrs	Follow strict infusion routine for safety
	Resentful of time spent on HPN
_time to set up infusion	Choose start & finish times (day or night)
_HPN bag every night	Fully dependent on HPN to stay alive
	Lack of choice & feeling forced to comply with HPN routine
	Loss of freedom & social life at night
	Frustrated from being housebound at night
	Not accepting own situations
_HPN bag 4-5 nights a week	Choosing which night for HPN
	Partially dependent on HPN to stay alive
	Accepting own situations

HPN treatment	HPN Coping Strategies
Properties & dimensions	
Setting up HPN:	
_heavy weight of HPN bag, drip stand	Struggled to carry bag, drip stand & pump
& electrical infusion pump	upstairs & around the house

	Fearful of tripping over equipment	
	Restricted / reduced mobility at home	
	Difficulty in lifting the bag over drip stand	Poor physical health or concurrent disease
	(lack of physical strength from old age)	(loss of core abdominal muscles, arthritis in both hands)
_2 litres or more, + IV fluids	Disrupted sleep (frequent toilet visits)	
	(if also living with stoma)	
_rucksack for portable pump & infusion bag	Being able to go away from home for holidays	Choosing not to go away (having to take large amount of equipment)
_to be discrete & to disguise equipment	Fulfilling own desires	Unfulfilled own desires
	Satisfied with self-image	Dissatisfied with self-image
Confident to set up HPN	Becoming confident to set up HPN	Lack of self-confidence to set up HPN
	Able to self-care (living alone)	Dependent on carer (living with spouse / partner)
	Enjoyed independence at home	Loss of independence at home

HPN treatment	HPN Coping Strategies	
Properties & dimensions		
Deliveries from Homecare Company (HCC):		
_infusion equipment (drip stand, pump)	Realisation of space needed to store equipment at home	
	Self-involvement to sort out storage space	Accepting help & support to sort out storage space (spouse, partner or relatives)
_HPN feeds, IV fluid bags	Frustrated with large amount of space taken up at home	
_ancillaries (dressing packs, stoma appliances, sterile gloves)	Living with disruptions at home	
	Being reminded of own situations	
_home visits from HCC nurses to supervise , train & assess	Satisfied with nurse training at home	
	Becoming confident with aseptic technique	
Physical improvements:		
_from HPN	Improved appearance	
	Improved welling	
	Realisation of health changes by others	
	Enjoying being at home	
	Socialising with friends & at family occasions	
_jaundice from long term HPN	Accepting side effects from HPN	
	Lack of choice	
	Dependent on HPN to stay alive	



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Appendix 12 Theoretical memo - stoma characteristics

What process is at issue here?

The participants (P#1,3,5,7,8 & 9) described in details their '**experience living with the stoma, fistula or chronic diarrhoea** (for #5)**'.** Their experiences illustrated the properties of stoma (fistula or chronic diarrhoea) in terms of '**volume**' and '**frequency**'.

Under which conditions does this process develop?

All participants had no knowledge of what a stoma (or fistula) was before coming into hospital due to '**sudden illness**'. During their hospital stay recovering from '**surgery**', they had to learn to look after the stoma. By the time they went home, they had little time to prepare themselves on how to fit stoma care into their lives at home and socially.

How do(es) the research participant(s) think, feel, and act while involved in this

process?

All participants were troubled by the '**high volumes**' and '**frequent losses**' from stoma, fistula or chronic diarrhoea. They all noticed '**watery contents**' with '**undigested food**' in the losses so it was necessary to explore the impact and dimension of '**malabsorption of oral fluids and food**' on their '**general health**' in terms of '**loss of appetite**', feeling '**unwell**' and experienced '**dehydration**'.

When, why, and how does the process change?

All participants needed '**frequent access to toilet facilities**'. One participant (#7) continued to experience discomfort at stoma site long after she was discharged from hospital.

They all disliked the '**embarrassment**' experienced with '**leaks**' or if they had '**accidents**' when not able to get to the toilet in time. They found it '**upsetting**' to have '**leaks and accidents**' at home and when going out.

What are the consequences of the process?

All participants found the experience of '**Living with stoma**' '**upsetting**' and the extent of this feeling on their home and social life was explored further in order to understand the impact and dimension of '**high volumes**' on their '**wellbeing**'.

Whenever they went out, they needed '**easy access to toilet facilities**'. They often felt '**anxious to empty bag**' and were in fear of '**unpredictable leaks or accidents**'. They felt '**self-conscious with stoma bag**' when going out, and they often had '**disruptions at meal times**' in order to empty stoma / fistula bag or to relief watery diarrhoea.

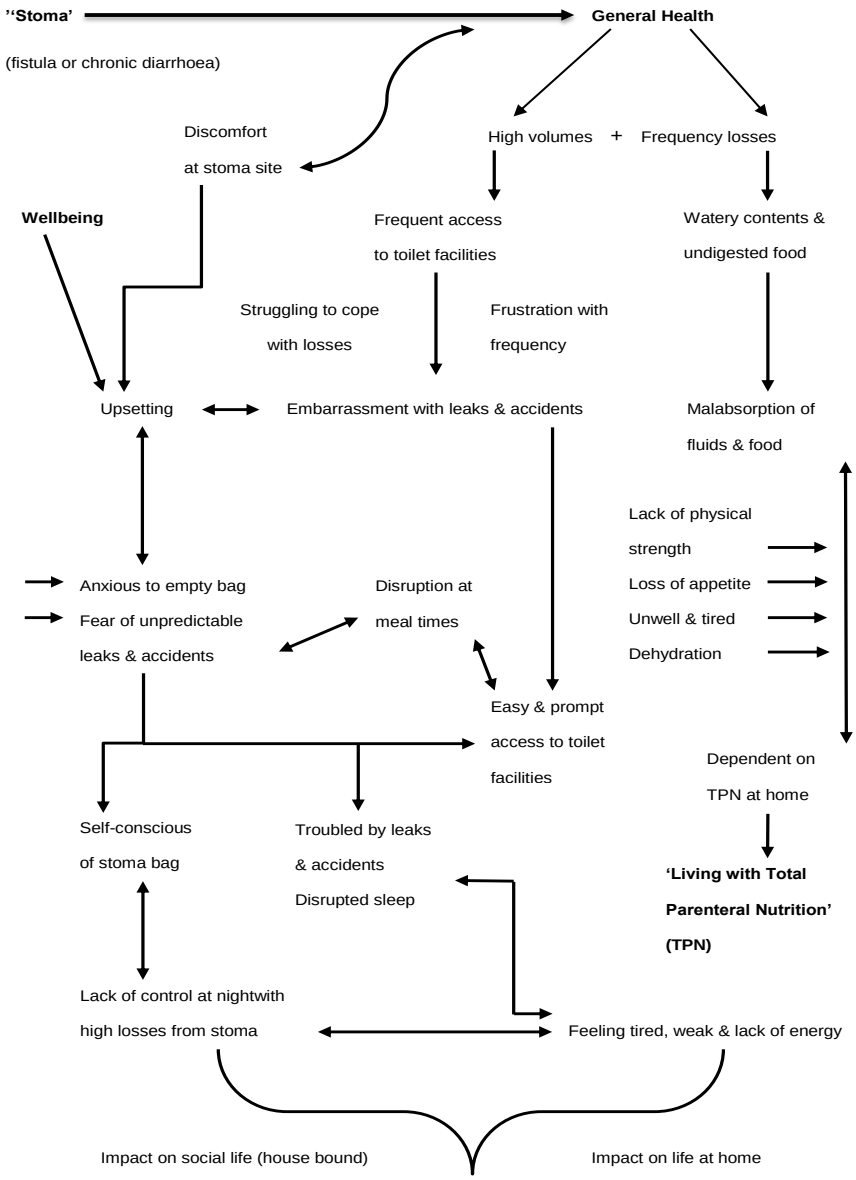
They also complained of '**having broken sleep**' from emptying the bags through the night, '**feeling tired constantly**' and '**weak**'. These experiences further demonstrated the dimensions of '**high volumes**' on their '**wellbeing**'.

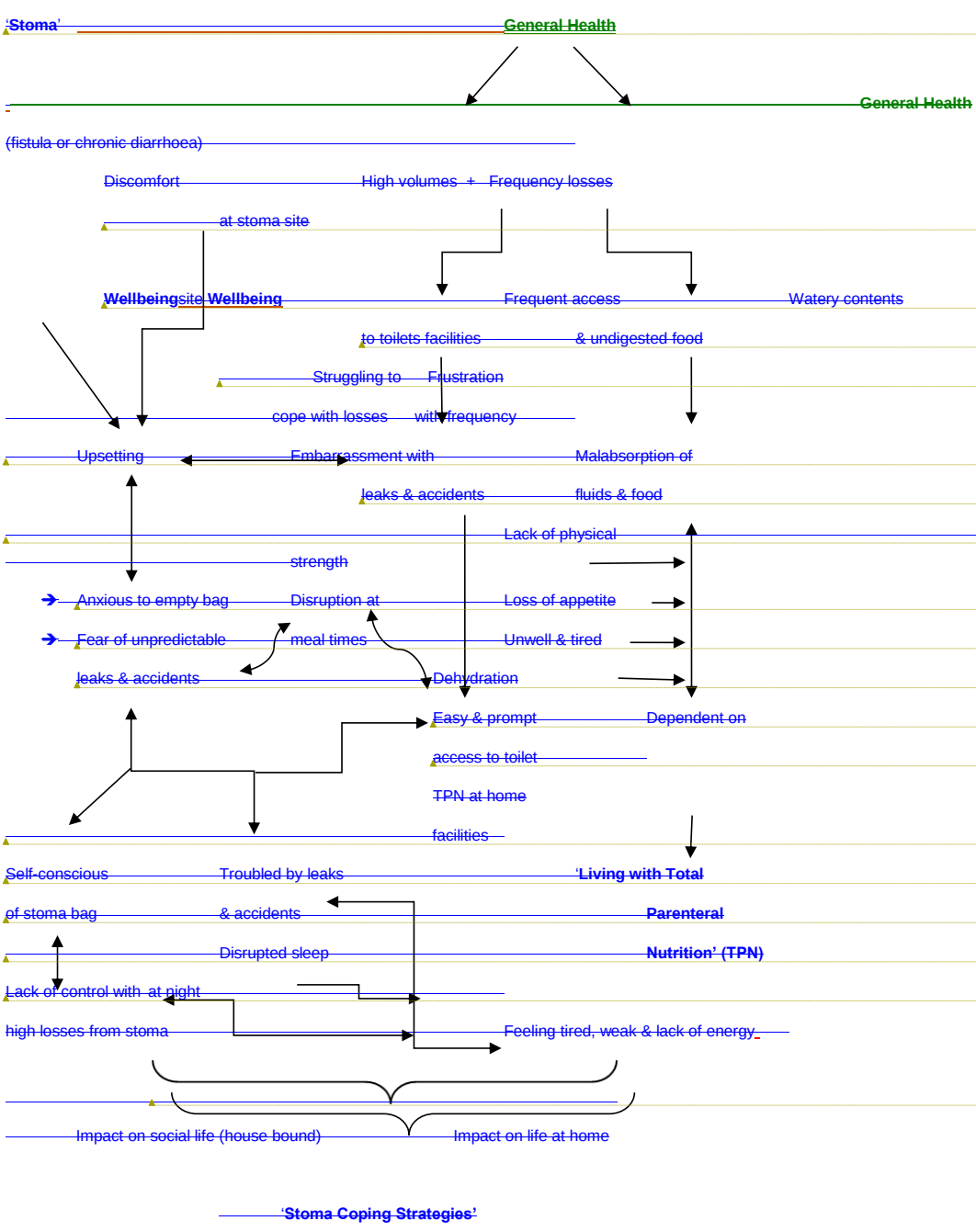
All participants found it '**difficult to control losses from stoma, fistula or chronic diarrhoea**'. This had led to a '**loss of social life**' in some cases, while others had become '**house bound**'. Their 'Stoma Coping Strategies' were explored further in the next section.

Category ‘Stoma Characteristics’ Thur 14.11.2013

Open codes on stoma characteristics (including fistula and chronic diarrhoea) were analysed across the same participants P#1,3,5,7,8 & 9 to discover the properties of ‘**Stoma Characteristics**’

Diagram 2 Properties of ‘Stoma Characteristics





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Appendix 13 Theoretical memo - living with HPN

01.12.2013

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Open codes from the same participants #1,3,5,7,8 & 9 were analysed to discover the two properties of 'HPN': 'Characteristics' and 'Coping Strategies'.

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Participant #5 had tpn at home from previous sudden illness. Following bowel restoration surgery, he developed chronic diarrhoea. He had to re-start HPN at home due to uncontrolled diarrhoea frequency and malabsorption of oral fluids and food.

P #9 underwent an operation to remove skin cancer on the abdominal wall. He suffered a complication from this procedure which led to a bowel fistula. The fistula produced high losses causing malabsorption of oral fluids and food. Subsequently he had to re-start HPN at home.

Open codes on 'HPN Characteristics' (P#1,3,5,7,8 & 9)

'HPN Characteristics' and 'HPN Coping Strategies'

Thur 02.01.2014

What process is at issue here?

The participants (P#1,3,5,7,8 & 9) described in details their 'experience living with HPN'. These experiences illustrated the 'HPN Characteristics' in terms of its properties in 'learning to set up TPN' when in hospital and in 'making changes at home for HPN' before going home.

PN itself required a set of routine and procedures that each participant needs to learn under the supervision and training from hospital nurse specialist at designated Teaching Hospitals. These aseptic techniques were non-negotiable, and they were integral to the safety of HPN at home. These routine and procedures must be followed meticulously by participants and by their main carer (spouse or partner) in order to prevent life-threatening infections. The Homecare Company (HCC) provided further training and assessment at the participant's home following discharge from hospital.

The method of axial coding was used to develop their properties and dimensions from the open codes abstracted from interview transcripts.

Under which conditions does this process develop?

There was one variation in the dependency on HPN amongst participants. This ranged from some participants (P#1, 3, 5, 8 & 9) who needed HPN (and IV fluids for #8) every night to one who only needed HPN on four nights a week (P#7). All participants recognised the life-saving effect of TPN. The difference in HPN frequency was determined by the severity of the participant's underlying health condition.

In other words they needed HPN daily to stay alive (see in-vivo quote from P#8, p.6, '*It rules your life; you've got to live around it. It's a case of you live or you die so everything revolves round it*').

One participant was too unwell (P#1) and one was in poor physical health (P#8) to set up HPN at home. These participants' spouse or partner became the main carer. They learnt to set up HPN at home.

The use of selective coding method revealed relationships between 'HPN Characteristics' and 'HPN Coping Strategies' in all participants. The participants described their 'HPN Coping Strategies' when staying in hospital for training, and when living in their own environment following discharge from hospital. This method was used to integrate and to refine the categories identified so far (Strauss & Corbin, 1989 p. 143).

How do(es) the research participant(s) think, feel, and act while involved in this process?

This study excluded the participant's spouse and partner from the interview. It was not intended to explore their views and experiences. However, for participants who were not living alone, they offered information about their spouse's and partner's perspectives in terms of their help and support in managing the HPN at home.

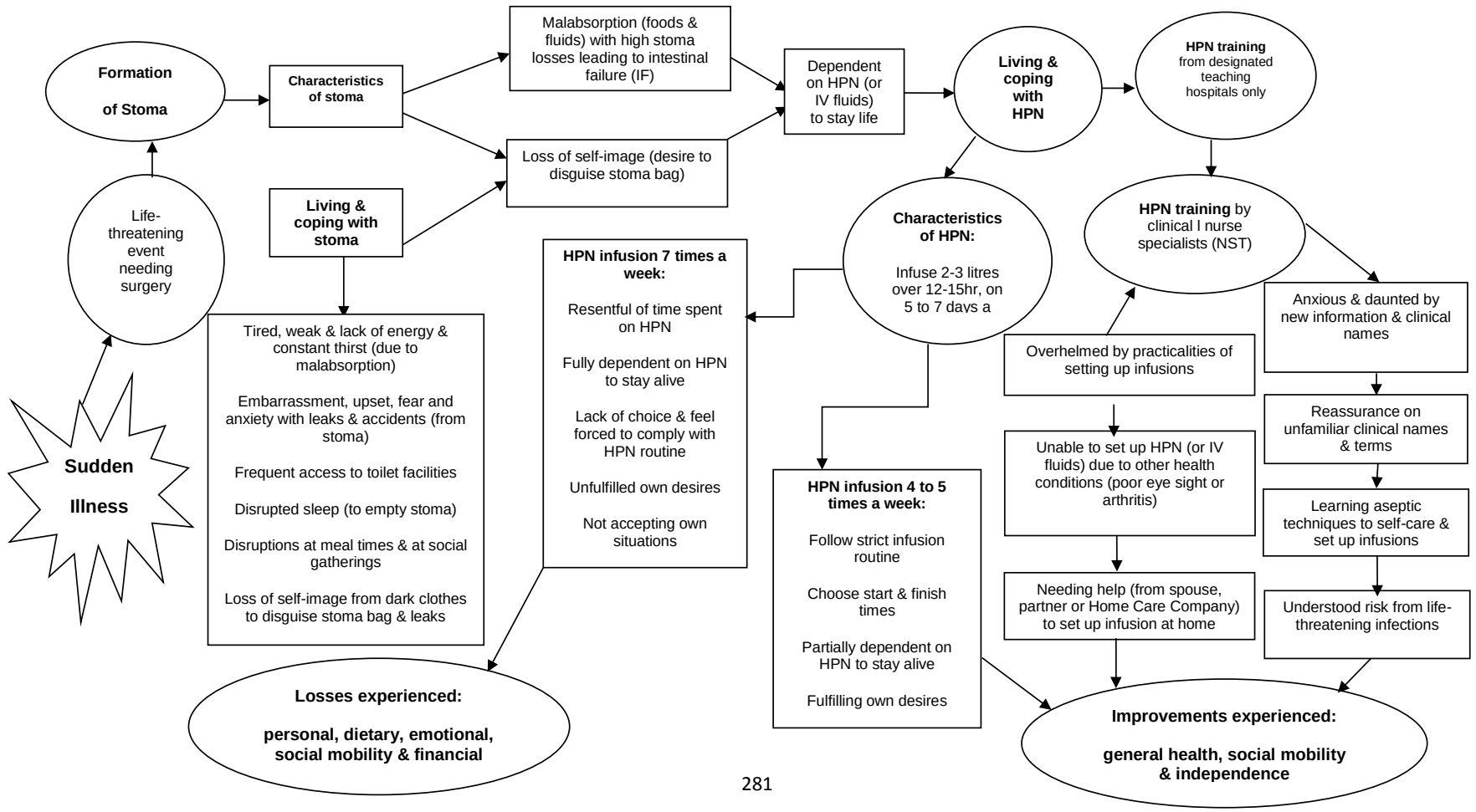
This level of disclosure by the participants offered insights into their 'HPN coping strategies' under the influence of their spouse and partner.

The use of selective coding method revealed differences in the 'HPN coping strategies' for participants who lived alone (P#3 & 5) versus those who lived with a spouse (P#1 & 9) or a partner (P#7& 8). This unique contribution would be explored further in subsequent interviews.

When, why, and how does the process change?
So far we've learnt that the 'HPN Characteristics' were the same for all participants with the exception of HPN frequency. The level of dependency on help and support from spouse and partner to set up HPN at home was not observed in the 'Stoma coping strategies' (see memo 3, diagram 3).

What are the consequences of the process?
Several participants commented on the heavy weight of the HPN bag (2 litres volume), the drip stand and the infusion pump all of which could contribute to the increased physical demand on the individuals. This could explain the dependency of some participants for help and support from spouse or partner. Open codes from participants who were older or were in poorer physical health from underlying condition or concurrent disease (#8 had no core abdominal muscles from original surgery and #5 suffered from severe arthritis in both hands since starting HPN at home) supported this notion. The unique contribution from the participant's age and other concurrent health condition / disease would be explored further in subsequent interviews.

Appendix 14 Theoretical memo - Generation of concepts from two main categories (stoma and HPN)



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Appendix 15 Summary of participants' characteristics

Gender (number)	**Male (4)**	**Female (8)**
Age range (yrs.)	**29 - 83**	
Mean age (yrs. mths)	**58.9**	
Median age (yrs.)	**63**	
Participants with 'Chronic ill health' (n = 3)		
Participants with 'Sudden illness' (n = 9)		

Appendix 16 Strengths of the research process

(Framework for assessing qualitative evaluations, national centre for social research, 2003)

Sample
How well defended is the sample design / target selection of cases / document

The strength of the study had been demonstrated by the inclusion of a diversity of participant characteristics (see Appendix15), making these findings relevant to patients with short bowel syndrome receiving HPN.

Data collection
How well was the data collection carried out?

Interviews were appropriate as they captured the experiences and lived meanings of the participant's everyday world (Kvale, 1996 p.70). The grounded theory was an appropriate choice of methodology because the research study aimed to explore the patients' actions and interactions with the processes of 'stoma care' and 'HPN treatment' following discharge from hospital. The process of joint data collection and data analysis demonstrated the principle of the constant comparative approach, which is was central to all grounded theory studies (Glaser and Strauss, 1967). The generation of categories and subcategories during data analysis was supported by use of theoretical sampling in the collection of subsequent interview data in order to develop the emerging theory (Corbin and Strauss, 2008).

Analysis
How well has the approach to, and formulation of, the analysis been conveyed?

The Straussian grounded theory approach to data analysis was followed in the development of more abstract concepts leading to the generation of theory of 'living with loss' (Corbin and Strauss, 2008). A detailed description of the research processes which explained the choice of methods used for participant selection, recruitment, data collection have been presented in chapter 3. The analysis of data which led to the generation of categories and subcategories in support of the central phenomenon has also been outlined fully in chapter 4. These discussions provided clarity and explanation of the choices and decision-trail decisions made by the researcher.

Ethics
What evidence is there of attention to ethical issues?

The researcher had taken into considerations the ethical issues associated with patients' involvement in the design of this qualitative research study to ensure that their rights and dignity was respected (Creswell, 2013; National Research Ethics Service, 2010), and the interviews were conducted with honesty and integrity (Kvale, 2007 p.29). The measures taken by the researcher to ensure that prospective participants were given the opportunity to speak to the researcher directly and to ask questions about the study during the recruitment process have had been discussed in chapter 3. None of the twelve study participants raised concerns or issues about their experiences with the researcher or with the interview itself.

Neutrality
Discussion of how error or bias may have arisen in design / data collection / analysis and how addressed, if at all.

The researcher's clinical role as non-medical prescriber of the nutrition support team for in-patients, who required PN, meant that the researcher was familiar with the clinical issues of stoma care and treatment with PN. This level of prior knowledge was used to ensure that the questions used in the interview guide were relevant and appropriate for this exploratory study. The phrasing of these questions was the same as those used in patient groups in clinical settings. The researcher's familiarity with the research topic had contributed to the individual's proficiency in exploring the participants' experiences in living with HPN (Kvale, 2007 p.49).

The potential for bias in the purposeful sampling of participants was minimised by ensuring that the researcher did not have direct clinical input in the provision of HPN care to any of the participants taking part in this study. This approach guarded against the researcher's deliberate attempts to select participants with the best or worse experiences with HPN (Creswell, 2013 p.154). The lack of familiarity between the researcher and the participants helped to maintain a neutral rapport and non-committal stance during the interview process (Denscombe, 2003 p.171).

Theoretical sampling is was an important feature in a grounded theory study. This technique was used to select participants for their relevance to the emerging categories and subcategories. The data provided ensured that the researcher was building up a strong foundation when developing and defining the relationships between the categories, subcategories and emerging concepts. Events and instances which were unique to a small number of participants were not excluded at the early stage of the analytic process (Corbin and Strauss, 2008). This was important to ensure that the variety and diversity of open codes, categories and subcategories generated were retained throughout the early stages of data collection and data analysis. Theoretical memos were written to facilitate these analytic processes.

Chapter 3 discussed in detail this 'open' approach had generated a wide range of relevant data during initial open coding keeping an open mind on new ideas, and minimising the tendency to arrive to a theoretical concept before all the major categories were developed. These initial open codes were refined, although some were not being pursued, during constant comparative analysis as the categories and subcategories were being developed to support the central phenomenon of 'living with losses.

Each audio-taped recording was transcribed verbatim by the researcher within one week of the interview. This was a very time consuming process, but it was a valuable part of the data analysis. During the transcribing of each recorded interview, the researcher was brought 'close to the data' as the researcher listened to the audio-tape recording. This in turn brought the participant's talk to life again facilitating a deep level of understanding through data immersion by the researcher (Denscombe, 2003 p.193). The participant's emotion was difficult to express in the transcription, so having heard what the individual was saying this was extremely useful for the researcher in the development of theoretical sensitivity during the process of initial open coding. With the use of theoretical memos, they provided context to the participants' description of their emotions and experiences with 'stoma care' and 'HPN treatment'. This was helpful for the researcher in developing objectivity and insight on the 'trajectory of events and instances' during joint data collection and data analysis (Kvale, 1996 p.64). These approaches reflected he Glaserian grounded theory whereby the researcher asked the question of 'what do we have here' (Stern, 1994 p.220).

Appendix 17 Approval letter from National Research Ethics Service

Health Research Authority

National Research Ethics Service

NRES Committee North West - Greater Manchester North
3rd Floor, Barlow House 4 Minshull Street
Manchester
M1 3DZ Tel: 0161 625 7817
Fax: 0161 625 7299
Email: cynthia.carter@northwest.nhs.uk

Ms Christina Wong
Consultant Pharmacist
Sheffield Teaching Hospitals NHS Foundation Trust Northern General Hospital
Herries Road S5 7AU

09 August 2012 Dear Ms Wong

Study title:	**Home parenteral nutrition in South Yorkshire: A qualitative study exploring the views and experiences of adult patients**
REC reference:	**12/NW/0554**

Thank you for your email dated 06 August 2012 responding to the Proportionate Review Sub Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the Sub Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Advertisement	1	16 February 2012
Covering Letter	1	06 August 2012
Interview Schedules/Topic Guides	1	16 February 2012
Interview Schedules/Topic Guides	1	16 February 2012
Investigator CV		29 May 2012
Letter of invitation to participant	2	01 August 2012
Other: CV Chiemeka		29 May 2012
Other: CV Lucas		29 May 2012
Other: CV Wood		14 June 2012
Other: DPharm Proposal	1	16 February 2012
Other: Grounded Theory Process	1	16 February 2012
Other: Tasks and responsibilities of coinvestigators	1	16 February 2012
Other: Participant Recruitment Log	1	16 February 2012
Other: Participant Interview Log	1	01 August 2012
Other: STH Lone Worker Policy	2	11 January 2012
Participant Consent Form	2	01 August 2012
Participant Information Sheet	2	01 August 2012
Protocol	1	16 February 2012
REC application	3.4	29 May 2012
Referees or other scientific critique report	1	29 March 2012
Response to Request for Further Information	1	06 August 2012
Summary/Synopsis	1	16 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports Notifying the end of the study
-
-

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0554 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Peter Klimiuk
Chair

Dr Peter Klimiuk
Chair

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Dr Peter Klimiuk
Chair

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This letter has been signed electronically. If you require a wet ink version please request one from the Committee Co-ordinator by email and it will be sent in the post.

E-Submission and E-Booking of REC applications available soon in IRAS – please refer to the HRA website for announcements at http://www.hra.nhs.uk/hra/hra-news-and-announcements/iras-four-years-on-celebrating-and-building-on-success/

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Dr Beverley Lucas, Senior Lecturer, University of Bradford
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Mrs Angela Pinder, Research Coordinator, R&D office for Sheffield Teaching Hospitals NHS Foundation Trust angela.pinder@sth.nhs.uk